

## **Connect for Care 2019: The International Meeting for Rare Disease Nurses**

**Meeting theme:** The Pivotal Role of Nurses in Integrated Rare Disease Patient Care

**Dates:** Sunday 24 – Tuesday 26 November 2019

**Venue:** Park Inn by Radisson, Amsterdam, The Netherlands

### **Meeting objectives:**

#### **1. Engage:**

- Understand the implementation of integrated personalised care and identify examples of best practice
- Explore the role of the nurse role within multidisciplinary teams

#### **2. Inform:**

- Provide tailored, disease-specific education and practical, hands-on training, e.g. through breakout sessions
- Review the current nurse-led research landscape (not to include discussion on treatment and therapies)

#### **3. Empower:**

- Provide tools to raise the nurse's profile within the multidisciplinary team
- Empower nurses to engage in regional rare disease nurse networks

| 25 <sup>th</sup> Nov | Day 1  |
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| 08:30–08:50          | <p><b>Plenary session – Co-chairs’ welcome and introduction</b></p> <ul style="list-style-type: none"> <li>• Welcome to the meeting</li> <li>• Introducing the meeting theme and general objectives</li> <li>• Ice-breaker activity: <ul style="list-style-type: none"> <li>○ To take place on iPads</li> </ul> </li> <li>• Highlights of the agenda <ul style="list-style-type: none"> <li>○ Encourage delegates to engage in the coffee break activities, including the STEP UP BPR poster/activity [TBC] (provide top-line info on STEP UP)</li> </ul> </li> <li>• Word cloud engagement</li> <li>• Housekeeping</li> </ul>   |
|                      | <p><b>Session 1: Integrated care in rare diseases today</b></p> <p>[Overall session objective: Engage and empower]</p>   |
| 08:50–09:10          | <p><b>Plenary session – What does integrated care in rare diseases look like?</b></p> <p><i>Presentation to include:</i></p> <ul style="list-style-type: none"> <li>• <i>Definition/explanation of personalised and integrated care</i></li> <li>• <i>Different formats of integrated care (e.g. horizontal vs vertical integration)</i></li> <li>• <i>Integrated care in rare diseases – what does it look like?</i></li> <li>• <i>What integrated care means:</i> <ul style="list-style-type: none"> <li>○ <i>to the rare disease patient</i></li> <li>○ <i>to the nurses</i></li> <li>○ <i>to the healthcare system</i></li> </ul> </li> </ul> <p><i>Session to conclude with a case study</i></p> <p>[Educational objective: To refresh nurses’ knowledge of the current standards in connected care and highlight its importance in rare disease nursing.]</p>  |
| 09:10–09:50          | <p><b>Roundtable session – Integrated care around the world</b></p> <p><i>Delegate grouping: delegates seated at tables according to country/regions and specialism (table plan defined at entrance, so delegates don’t need to change seats for this session). This will be arranged closer to the meeting to allocate all attendees a table.</i></p> <ul style="list-style-type: none"> <li>• Delegates to explore the current scenario of integrated care in their countries, including: <ul style="list-style-type: none"> <li>○ Is there an integrated care plan in place at their clinical practice?</li> <li>○ Identify examples of best practice as well as areas for improvement</li> <li>○ Practical steps to implementing improvement (e.g. identify barriers/needs and suggest solutions)</li> <li>○ Any specialism specific examples of best practice</li> </ul> </li> <li>• A worksheet with suggested topics for discussion will be provided to guide the session.</li> <li>• Each table to submit their conclusions through their iPad <ul style="list-style-type: none"> <li>○ Selected responses to be read by the session chair to the wider plenary group at the end of the session</li> <li>○ All responses to be available via the iPads post-session to enable</li> </ul> </li> </ul> |

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|                           | <p>delegates to have more in-depth information about the state of integrated care in the different countries <i>[would require CMLR approval onsite]</i></p> <ul style="list-style-type: none"> <li>○ A world map will be displayed on the main screen and colour-coded in real-time with the answers from the countries. Delegates to select from pre-defined colour coded statements what best describes the current situation in their countries and icons to visually represent availability of an integrated care plan. <ul style="list-style-type: none"> <li>▪ Alternative to have a pinboard where delegates pin a colour that best represents the state of integrated care in their country.</li> </ul> </li> <li>○ Option for the world map with the delegates' conclusions to be mirrored in a touch screen in the coffee area where delegates can explore the different types of integrated care systems around the world and get some new ideas to take home – <i>not currently budgeted for [would require CMLR approval onsite]</i></li> </ul> <p>[Educational objective: To discuss current standards for integrated care on a regional level as a means of raising standard of care by sharing examples of best practice and identifying practical steps that can be taken for areas requiring improvement]</p>  |
| <p><b>09:50–10:30</b></p> | <p><b>Coffee break, poster session and networking</b></p> <p><b>Posters: Inspiring examples of your work</b></p> <p><i>Prior to the meeting, delegates are encouraged to submit posters illustrating their work and/or research in lysosomal storage disorders, immunology and haematology. All submitted posters will be displayed throughout the duration of the meeting and classified into categories (e.g. Everyday nursing, Research, Integrated care). Augmented reality feature to be included in this session, where delegates will be able to use iPads to scan the posters for further information. This could include a video of the author, a quiz based on the information provided in the poster, additional poster information, or a figure or table.</i></p> <p><i>Certificates will be provided to nurses for poster submission and acceptance.</i></p> <p><b>Activities:</b></p> <ul style="list-style-type: none"> <li>• STEP UP for Rare Care dedicated area [TBC]</li> <li>• Connect for Care Hall of Fame [wall panel where delegates can leave a testimonial] – <i>not currently budgeted for</i></li> <li>• A walk through a patient's journey [corridor type setting taking the delegate through a patient journey] – <i>Takeda may already have some material – not currently budgeted for</i></li> <li>• Touchscreens with tips and suggestions to implement integrated personalised care [TBC – <i>not currently budgeted for</i>] <ul style="list-style-type: none"> <li>○ Possibility to include a quiz on research topics – can also be made available on the iPads only</li> </ul> </li> <li>• Dedicated space for delegates to meet using the matchmaking feature on the iPads</li> </ul> |
| <p><b>10:30–10:50</b></p> | <p><b>Plenary session – The pivotal role of the nurse in coordinating care</b></p> <p><i>Plenary session with Q&amp;A</i></p> <p>To include discussion on:</p>  |

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|                           | <ul style="list-style-type: none"> <li>• The nurse as the central hub of patient care coordination</li> <li>• The role of the nurse in the continuum of care</li> <li>• Ensuring quality, safety and efficiency in care</li> <li>• Coordination of care centred on the needs and preferences of patients</li> </ul> <p><i>[Delegates will be invited to submit questions for discussion via the iPads]</i></p> <p>[Educational objective: explore the roles of rare disease nurses in coordinating integrated patient care, and how it can lead to advancing best practice]</p>  |
| <p><b>10:50–11:20</b></p> | <p><b><i>Interactive plenary session – Inside an MDT meeting</i></b></p> <p><i>Plenary session</i></p> <p><i>Session to discuss strategies to help nurses shape decisions around patient care, acting as the patient voice. To explore nurse-patients/caregivers and nurse-other HCPs relationship.</i></p> <p><i>Session to include tips for efficient care coordination across the various specialisms involved and that can be transferrable to nurses who are not part of an MDT</i></p> <p>[Educational objective: Explore the role of the nurse as a central coordinator of care and key influencer in patient care related decisions]</p>   |
| <p><b>11:20–11:50</b></p> | <p><b><i>Breakout session – The evolving role of the nurse in the patient journey</i></b></p> <p><i>Delegate grouping: same as before [delegates seated at tables according to country/regions and specialism (table plan defined at entrance, so delegates don't need to change seats for this session). This will be arranged closer to the meeting to allocate all attendees a table.]</i></p> <ul style="list-style-type: none"> <li>• Delegates to discuss the role of the nurse across a general patient journey, considering: <ul style="list-style-type: none"> <li>○ Current nurse responsibilities at their clinical practice, including everyday aspects of care</li> <li>○ Day-to-day coordination of patient care</li> <li>○ Presence/absence of a multidisciplinary team</li> </ul> </li> <li>• To include a call to action: what needs to change and areas for improvement</li> <li>• Delegates will be provided with: <ul style="list-style-type: none"> <li>○ A worksheet with topics to guide discussions</li> <li>○ An A2 workmat to be populated with the patient journey and main conclusions from discussions</li> </ul> </li> </ul> <p><i>Workmats to be displayed at the back/side of the plenary room for the duration of the meeting</i></p> <p>[Educational objective: Encourage peer interaction and discussion around day-to-day coordination of care, as a mean to improve patient outcomes]</p> |

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| <b>11:50–12:05</b> | <p><b>Reflections on key takeaways</b></p> <p>Quiet reflection time to provide an opportunity for delegates to reflect and discuss key learnings from sessions and how the learnings can be transferred to their everyday practice. To end with a 5 min table discussion where delegates share their takeaways.</p> <ul style="list-style-type: none"> <li>• Option to use postcards as an enduring material and reminder of individual pledges, that can be posted to the delegates after the meeting – <i>postage not currently budgeted for</i></li> </ul>   |
| <b>12:05–12:15</b> | <p><b>Session 1 summary and close</b></p> <p><i>To include a reflection on key takeaways from the morning session</i></p>   |
| <b>12:15–13:05</b> | <b>Lunch, poster session and networking</b>   |
|                    | <p><b>Session 2: What's new in rare diseases</b><br/> [Overall session objective: Inform and empower]</p>   |
| <b>13:05–13:25</b> | <p><b><i>Specialism-specific parallel plenaries – 2019 in review: an overview of nursing publications and the research landscape</i></b></p> <p><i>Parallel plenaries with Q&amp;A</i></p> <p>To include an overview and discussion on:</p> <ul style="list-style-type: none"> <li>• Relevant nursing research published over the past year</li> <li>• Current areas of research</li> <li>• Where to find information on current research</li> <li>• Contributing to and initiating research projects</li> </ul> <p>[Educational objective: Engage, inform and empower nurses with the latest nursing publications relevant for the specialism and provide tools to find the latest information]</p>  |
| <b>13:25–13:50</b> | <p><b><i>Specialism-specific open discussion – What does the future hold – aspirations in Haemophilia/ LSD/ PID nursing?</i></b></p> <p><i>Moderated structured parallel open discussions (campfire session). Minimal to no slides to encourage discussion</i></p> <p>To include discussions on what the delegates would like to see happen in their role, and for their patients over the next decade, including:</p> <ul style="list-style-type: none"> <li>• How they would like their role to evolve</li> <li>• What are the key unmet needs that need to be overcome for their patients?</li> <li>• What are the current challenges that need to be overcome to realise these aspirations?</li> </ul> <p>[Educational objective: Explore the aspirations of the delegates relating to their role as specialist nurses and the outcomes for their patients]</p> |
| <b>13:50–14:05</b> | <b>Coffee break</b>   |
| <b>14:05–15:05</b> | <b><i>Specialism-specific mini plenaries – Hot topics in rare diseases!</i></b>   |

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|                    | <p><i>Short presentations (15 min each) covering current hot topics in the rare disease field.</i></p> <p>Topics to be suggested by the steering committee/session speakers</p> <p>[Educational objective: Enhance nurses' expertise in current hot topics in the rare disease field and exchange knowledge to improve patient care]</p>   |
| <b>15:05–15:25</b> | <p><b><i>Specialism-specific parallel plenaries – Implementing best practice in everyday nursing</i></b></p> <p><i>Parallel plenaries with Q&amp;A</i></p> <p>To include discussion on:</p> <ul style="list-style-type: none"> <li>• Evidence-based best practice and empirical best practice</li> <li>• What is best practice in [specialism]?</li> <li>• Overcoming barriers to implement best practice</li> <li>• Disseminating best practice – involving staff and clinicians</li> <li>• Guidance on becoming best practice champions</li> </ul> <p>NOTE: The Heam session to include information on the STEP UP Best Practice Report, including a short (~10 min update) on relevant information such as study design and key findings.</p> <p><i>Guidance on best topics to explore to be provided by the Steering Committee.</i></p> <p><i>Opportunity for the Haematology group to explore STEP UP for Rare Care in this session</i></p> <p>Session to end with a call to action for best practice champions</p> <p>[Educational objective: Enable high-level discussions of specialism-specific subjects and share practical insights to be implemented in clinical practice]</p> |
| <b>15:25–16:10</b> | <b>Coffee break, poster session and networking</b>   |
| <b>16:10–16:20</b> | <p><b>Reflection on key takeaways</b></p> <p><i>Same format as previously</i></p>  |
| <b>16:20–16:45</b> | <p><b><i>Guest speaker – Understanding and managing non-adherence in clinical practice</i></b></p> <p>[Educational objective: Share key learnings on the value of nurse-led empathy as a mean to improve patient's adherence to treatments]</p>  |
| <b>16:45–17:00</b> | <b>Close of Day 1 and preview of Day 2</b>   |
| <b>19:00</b>       | <b>Evening dinner</b>  |

| 26 <sup>th</sup> Nov                      | Day 2   |
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| 08:30–08:35                               | <p><b>Welcome to Day 2</b></p> <p><i>Plenary session</i></p> <ul style="list-style-type: none"> <li>• Brief recap of Day 1</li> <li>• Highlights of the agenda</li> </ul>   |
|   | <p><b>Session 3: Shaping the future of rare disease nursing</b></p> <p>[Overall session objective: Engage and empower]</p>  |
| 08:35–09:15                               | <p><b><i>Delegates case studies – Real-life examples of integrated care in rare diseases</i></b></p> <p><i>Submitted delegates’ case studies on integrated care in rare diseases to be presented, followed by Q&amp;A.</i></p> <p>Maximum of 3 case studies to be presented. To include time for table discussions on how applicable the learnings from the case studies are to the delegates’ practice.</p> <p>[Educational objective: Provide real-world examples of integrated care in a rare disease setting and the impact it has on patient care]</p>   |
| 09:15–09:55<br><i>20 min per workshop</i> | <p><b><i>Parallel workshops – Supporting coordination of integrated care through the use of technology</i></b></p> <p>Delegates to attend <u>2</u> workshops on:</p> <ul style="list-style-type: none"> <li>• Disease monitoring apps and improved patient treatment adherence</li> <li>• e-clinics and patient phone lines</li> <li>• Remote patient monitoring</li> <li>• Tracking people through transitions – electronic health records</li> </ul> <p><i>Speakers to rotate rooms and adapt discussion topics to the different groups. Delegates to be split according to level of integrated care as determined by the pre-meeting survey.</i></p> <p>[Educational objective: Engage, inform and empower nurses with the latest technology tools and training]</p> |
| 09:55–10:35                               | <p><b>Coffee break, poster session and networking</b></p> <p><i>Same format as in Day 1</i></p>   |
| 10:35–11:15<br><i>20 min per workshop</i> | <p><b><i>Parallel workshops – Supporting coordination of integrated care through the use of technology</i></b></p> <p><i>Continued. Delegates to attend the remaining <u>2</u> workshops</i></p>  |

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| <p><b>11:15–11:45</b></p> | <p><b><i>Interactive panel discussion – How can we shape the future of rare disease nursing?</i></b></p> <p><i>Panel discussion</i></p> <p>Delegates will be invited to participate by submitting questions or comments or voting on key topics to focus on. There is potential to pose these questions in advance via the pre-meeting survey for additional engagement.</p> <p>[Educational objective: To support delegates in their role as leaders for driving change and shaping rare disease care in their regional centres.]</p> |
| <p><b>11:45–12:10</b></p> | <p><b>Panel discussion – The role of the nurse in guiding and supporting the end-to-end patient journey</b></p> <p><i>Two nurses to discuss ethically challenging case studies, with the participation of the audience by submitting comments and questions via the iPads. An ethicist to introduce each case study, moderate discussions and comment at the end of each case study</i></p> <p>[Educational objective: To upskill nurses with tools to communicate and guide patients through decisions on therapeutic solutions]</p>  |
| <p><b>12:10–12:25</b></p> | <p><b>Reflection on key takeaways</b></p> <p><i>Same format as previously</i></p>  |
| <p><b>12:25–12:40</b></p> | <p><b>Meeting summary and close</b></p> <ul style="list-style-type: none"> <li>• Meeting evaluation</li> <li>• Closing words from meeting Co-chairs</li> <li>• Bringing it back to the patient <ul style="list-style-type: none"> <li>○ Option to have a short patient video reflecting on how valuable the specialist nurse has been in managing their disease – <i>not currently budgeted for</i></li> </ul> </li> </ul>   |
| <p><b>12:25–12:40</b></p> | <p><b>Takeda closing words</b></p> <p>[Photo montage]</p>  |