2023 Annual Leadership Summit, Milan, Italy

Day 1 – June 17, 2023

9:00 AM   Welcome. Goals of the meeting
           June Kinoshita, FSHD Society
           Zoom host: Leigh Reynolds

9:05 AM   Ice breaker - getting to know one another
           Sheila Hawkins, FSHD EU

10:00 AM  Medical care standards for FSHD
           Nicol Voermans, MD PhD,
           Radboud Medical Center

10:30 AM  Q&A

10:45 AM  Break

11:00 AM  Research highlights from the International
           Research Congress on FSHD
           Alexandra Belayew, PhD,
           University of Mons

11:30 AM  Drug development & clinical trial overview
           Jamshid Arjomand, PhD, FSHD
           Society

12:00 PM  Q&A

12:30 PM  Lunch

1:30 PM   Project Mercury overview:
           Mark Stone, FSHD Society

2:00 PM   Q&A
           Moderator:

2:30 PM   TREAT-NMD and international registries
           David Allison, PhD, TREAT-NMD

2:50 PM   Q&A

3:00 PM   Break

3:15 PM   Challenges of access to future therapies
           Josie Godfrey, Project HERCULES

3:45 PM   Q&A

4:00 PM   Break

4:15 PM   Patients and Industry dialog on clinical trials
           Moderator: Josie Godfrey

5:15 PM   Summary of day / prepping for Day 2
           Moderator: Ricardo Gerpe, FSHD
           Spain

5:30 PM   Adjourn and Break

7:00 PM   Dinner
### Day 2 – June 18, 2023

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Moderator(s)</th>
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<tbody>
<tr>
<td>9:00 AM</td>
<td>Welcome. Recap Day 1. Day 2 goals</td>
<td>Sheila Hawkins; Zoom host:</td>
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<td>Leigh Reynolds</td>
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<td>9:15 AM</td>
<td>World Alliance areas of focus</td>
<td>Moderator: Sheila Hawkins</td>
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<td>Each organization to define outcomes that best fit its local conditions and organizational interests and capacity.</td>
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<td>10:15 AM</td>
<td>Break</td>
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<tr>
<td>10:45 AM</td>
<td>Breakout groups by areas of focus:</td>
<td>There will be parallel Zoom</td>
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<tr>
<td></td>
<td>- Patient education and engagement</td>
<td>breakout rooms per topic.</td>
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<td>- Clinical resources and clinician engagement</td>
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<td>- Registries and research</td>
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<td>- Advocacy, access to treatments</td>
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<td>- Sustainability</td>
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<tr>
<td>11:45 AM</td>
<td>Task forces present their goals and plans</td>
<td>Moderator:</td>
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<tr>
<td>12:15 PM</td>
<td>Looking forward</td>
<td>Mark Stone</td>
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<td>12:25 PM</td>
<td>Adjourn</td>
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