



HOPE & HAPPINESS ARE PART OF THE TREATMENT

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EURORDIS

19 May 2017, EURORDIS Membership Meeting, Budapest

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THE QUEST FOR A HOLISTIC APPROACH TO BEING WELL

2 pm

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2 pm	<p>Introduction by Yann Le Cam: objectives of the session</p> <p>Introduction by participants: motivation & expectation</p>
2: 30 pm	<p>Presentation of RareBarometer Voice results on the use and practice of respondents (Sandra)</p> <p>Explore the diversity and extent of approach used by participants</p>
2:50 pm	<p>Presentation of RareBarometer Voice results in the health and cost impact as perceived by respondents</p> <p>Discussion on higher potential and higher risks</p>
3:10 pm	<p>Presentation of the case of acupuncture on different pain (Tuy Nga)</p> <p>Presentation of the case of osteopathy in duchenne boys in wheelchair (Tuy Nga)</p>
3:20 pm	<p>Evidence Based Medicine</p> <p>WHO Health definition & SDGs 2030</p> <p>Integrated care and holistic approach</p> <p>Role in individual strategy of life, in empowerment</p> <p>ERNs & Guidelines of Diagnostic & Care</p>
3:40 pm	<p>Which action for EURORDIS?</p> <p>Are alternative and complementary medicines and therapeutic approaches, a potentially important topic for EURORDIS members to work more on together?</p> <p>Do we need further analysis of use, extent, impact, expectations from patients (RareBarometer)?</p> <p>Do we need further case reports (Access campaign)?</p> <p>Should we integrate it in our advocacy? Integrated care? Holistic Approach to « care »? Research?</p> <p>Should we develop a Charter in few key points?</p>
4 pm	<p>Conclusion</p>