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Oral Presentation

Development of Clinical Guidelines for the Management of Communication in Individuals with Rett Syndrome

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Background: The number of specialist centres for the care & management of individuals with Rett syndrome (RTT) is growing internationally as is the number of clinicians with specialist skills working independently or in local teams. However, there is huge variability in knowledge/expertise and clinical practice between & within countries. Guidelines are needed which provide information to families and which can be followed by clinicians. Following ERSCM2013 an international work group (the authors) was formed to guide such a project.

Aims: To develop international clinical guidelines for communication (assessment, intervention & long-term management) in individuals with RTT.

Method: Based upon well-established practices for the creation of evidence-based guidelines through a consensus approach, this project follows the methodology used to develop the scoliosis and growth & nutrition guidelines. Following a review of existing Rett databases, the approach includes reviewing published & grey literature, creating an inventory of clinical practices, extracting themes & statements upon which to draft guidelines, and applying the Delphi process amongst a core of experts to finalise them.

Results: A review of existing databases has demonstrated shortcomings in data collection relevant to the creation of standard guidelines for communication. During the congress an overview of the literature to date (relevant to the management of communication) and of clinical practices in a range of countries will be presented, together with an approach for adopting international guidelines in the near future. Family members & professionals will be recruited to participate in the consultation groups required at later stages of the project.

References:

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