Project announcement: Development of clinical guidelines for the management of communication in individuals with Rett syndrome.

We are delighted to announce the start of an international project, funded by a HeART research grant from rettsyndrome.org, to develop clinical guidelines for the management of communication in individuals with Rett syndrome.

The idea for the project took shape following the third European Rett Syndrome Conference in Maastricht in October 2013. During the next two years the project will be led by the Rett Expertise Centre Netherlands (Gill Townend and prof. dr. Leopold Curfs ), with the core work group also including Dr. Theresa Bartolotta (USA), Helena Wandin (Sweden), Anna Urbanowicz (Australia) and Sally-Ann Garrett (UK and Ireland). The project will combine available evidence with expert consensus, following the model used to develop guidelines for the management of scoliosis, nutrition and growth, and most recently bone health, in Rett syndrome.

We need your help now in two ways:

1. We need to be able to contact experts in the field of communication and Rett syndrome to participate at various stages of the project. Their knowledge and experience is fundamental to the successful development and eventual implementation of guidelines for the management of communication in Rett syndrome. We hope to draw on the experience of professionals from as many countries as possible.

   Please recommend to us any professionals (or tell us if you are a professional) specialising in this area. That is, any speech and language therapists/pathologists or other therapists/educators with specialist skills in communication, who are experienced in working with individuals with Rett syndrome. They may offer communication assessment, advice, intervention and/or therapy as a member of a specialised team or may work in independent practice. Please send us their names and email addresses/phone numbers (with their agreement that you may do so) so that we can make contact with them.

2. We are currently engaged in a review of both published and unpublished literature in relation to communication and Rett syndrome. We hope to gather as much material as possible from as many countries as possible.

   Please send us a copy of anything you think may be relevant to our search (or a link to it/reference of where to find it). By this, we are thinking especially of materials that would not be available to us through the usual online searches of peer-reviewed journals. For example, guidelines and policies written as working documents at a local or national level, conference proceedings and seminar presentations/workshops. All of these must of course refer to Rett syndrome but could cover a range of aspects in relation to communication. For example, early and ongoing development of communication, assessment, therapy/intervention, strategies to facilitate communication etc. The documents can be in any language. If a translation into English is not provided we would be grateful for your recommendation of someone who could translate the document for us.

Please send any information by email to Gill Townend - g.townend@maastrichtuniversity.nl or any other member of the core work group:
Theresa Bartolotta - Theresa.Bartolotta@stockton.edu
Sally-Ann Garrett - sallyann.garrett2@btinternet.com
Helena Wandin - helena.wandin@regionjh.se
Anna Urbanowicz - a.urbanowicz@uq.edu.au

Please share news about the project, and our request for information, with your friends and colleagues. Their contribution to the project, as well as yours, is important to us. We need your input to make the guidelines a reality.
Thank you!

Gill Townend and Leopold Curfs (on behalf of the core work group)
Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre, The Netherlands

References: