Interstage mortality after Stage 1 Norwood palliation; Adopting the Wisconsin model to Norway.

Objectives: As survival increases after palliation for HLHS (Hypoplastic left heart syndrome), increasing attention has been focused on decreasing perioperative morbidity and interstage mortality. Feeding problems represent a significant cause of morbidity in these patients. We have already adopted a strategy of aggressive perioperative enteral feeding in all our patients with HLHS or related malformations, and followup by a nurse-coordinator. We decided to adopt the Wisconsin model regarding home-monitoring from December 2009, and to present the preliminary results from this approach.

Methods: We reviewed the medical records of the entire experience of 107 consecutive neonates at our institution undergoing palliation for HLHS or related malformations. Guidelines for feeding were given both written and orally by the HLHS coordinator to all persons involved. Weight control weekly, in addition to a pulsoximetery reading. A diary was given on discharge. The parents were obligated to call the HLHS coordinator once a week. This was performed until Stage 2 Palliation.

Results: Introducing the home-monitoring program from December 2009, the interstage mortality is 0. Intervention was done in 3 patients from December 2009, who required stenting of shunts, before changes in hemodynamics became obvious. Weightloss and failure to thrive, detected by the parents and reported to the HLHS coordinator, were their first symptoms.

Conclusions: Implementing the home-monitoring program as part of the existing close followup on HLHS patients, is essential to reduce interstage mortality. The role of a nurse-coordinator is pivotal and the building of relations supports this approach. It's all about care, building confidence and commitment.