

Poster presentation

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A Swedish national follow-up programme for children and adolescents with myelomeningocele

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Background

In 1998 a Swedish national follow-up programme for children and adolescents with myelomeningocele (MMC), with focus on neurogenic bladder and bowel dysfunction was launched. In 2004, 600 children and adolescents with MMC from 0 - 18 years of age were included in the programme and the needs for further medical follow-up after transition into adulthood for the cohort born 1986 - 89 has been presented (Olsson *et al* 2007). A subgroup of 39 children with MMC in the south-east region of Sweden born 1993 - 2003, was evaluated (Wide *et al* 2007), showing a high success in preventing renal damage when keeping to the proactive follow-up programme. The programme was evaluated and revised, now enlarged to include also other areas for follow-up e.g. neonatal care, gastroenterology, orthopedics, neurosurgery, endocrinology, cognition, sexuality, latex allergy, transition etc, also including guidelines for physiotherapy and occupational therapy. The programme will also include a national MMC-register. The aim is to get standardized evidence based national recommendations for the follow-up of children and adolescents with MMC from birth into adulthood.

Materials and methods

A network of professionals working with children with MMC has presented guidelines as far as possible evidence based, for the different areas of follow-up. Editors are neuro-pediatricians from the six university hospitals in Sweden. Regular cohort studies are planned for every 3-4 year period to follow the future development of the total MMC-population in Sweden.

Results

The first chapters are available on Internet (blf.net; neuro-pediatrisk, vårdprogram) on the site of the Swedish Neuro Pediatric Society, SNPF. A national register is under construction.

Conclusion

The Swedish national follow-up programme from 1998 for children and adolescents with neurogenic bladder and bowel dysfunction is after evaluation and revision, enlarged to include all aspects of follow-up for children and adolescents with MMC. The programme was launched January 2009 and is available on the Internet.