

Oral presentation

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## Bridging health care gaps for new survivors – a total population study of young persons with MMC

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### Background

Since the number of newborns with myelomeningocele (MMC) is decreasing a national network of neuropaediatricians with long experience of MMC has been founded in Sweden. Our first task was to identify the areas of medical concern in adolescents with MMC.

### Materials and methods

A total national population study has been performed. The first analysis concerns those born 1986 – 89 and is based on review of medical records.

### Results

175 adolescents born 1986–89 were living in Sweden on July 1<sup>st</sup> 2004, 86 females and 89 males. Their special medical characteristics are presented in Table I. Single symp-

toms and signs specifically/not specifically related to the MMC were recorded but not presented here.

### Conclusion

In Sweden approximately 40 adolescents with MMC will yearly reach adulthood the next decennium. A majority of them will have medical problems with need for a multi-disciplinary team approach in order to supply the best care in adulthood.

Table I

Individuals with MMC	No	%		No	%
Mental retardation (MR)	46	26	Recurrent urinary tract infections	27	15
Active epilepsy	24	14	CIC	149	85
Hydrocephalus	150	86	Anticholinergic medication	70	40
- Shunts	145		Surgery (eg Mitrofanoff)	42	24
- Ventriculocisternostomi	5		Incontinence pads	125	71
Tethered cord syndrome (Op)	62	36	Reduced kidney function	3	1,7
No independent walking indoors	92	53	Anal water irrigation	103	59
Walking with aids	35	20	MACE	17	10
Walking independently indoors	47	27	Gastrostomy	6	3,5
Orthopedic surgery/ortoses	128	73	Respiratory aids	5	3
Scoliosis (operated 44)	74	42	Recurrent bedsores	34	19