1. What has worked to predict/prevent adverse change? Imaging? UDS? 

   See discussion for Questions 2: No consensus, as proponents of conservative and proactive management will view things quite differently. Conservative management proponents would argue that imaging does not predict change but will demonstrate change and that said change is recoverable in most patients. Proactive proponents strongly value UDS as a predictor of risk of upper tract change prior to said change by US. US surveillance is valued in looking at the whole patient but nothing has been demonstrated as predictive of change. Renal scan useful for documentation of change but too late to predict/prevent.

2. Is proactive management better to maintain normal upper tract? What is proactive management?

   Multiple patient series and institutional experiences with conservative/expectant and/or proactive management have contributed to the literature. The majority are retrospective cohort studies and some are retrospective comparison studies. Only one is prospective but was non randomized (Edelstein) Unfortunately, there is no definitive answer. The studies are limited by diverse populations and variations in medical management and treatment thresholds, in addition to retrospective nature. The risk for renal damage appears to be present whether proactive or conservative management is promoted, with authors in both camps citing low numbers. The numbers in the proactive series are curiously a little higher (4-17%). The risk of cutaneous vesicostomy appears to be reduced in proactive management (7-17% in expectant groups)

   The one prospective but nonrandomized study from Edelstein et al was perhaps the most telling with 80% of the “expectant with risk factors” group having UT changes, vs 23% for expectant with no risk factors and 11-15% in the proactive cohorts. Vesicostomy was 7-9 % in expectant vs none in proactive (with the exception of Wu)

   Risk of bladder augmentation to protect the upper tracts appears to be less in proactively managed.

   To additionally complicate the data, proactive management may take 2 flavors: early intermittent catheterization for all (CIC) regardless of risk level vs CIC with or without anticholinergics initiated based upon baseline or updated urodynamic risk profile.

   A CDC funded prospective multi-institutional clinical management protocol for newborns has been developed. (Routh etal) The need for this protocol highlights the lack of clinical evidence to support early medical management and need for serial testing amongst newborns, infants and young children with myelomeningocele. Protocol is designed to be iterative, identifying failures/deviations from protocol required to identify patient groups in need of more intense management.
One additional point is whether prenatal vs postnatal closure portends a clear urologic advantage. While there is little long term data, the available data suggests that there is not a clear advantage in terms of need for CIC, medications or need for bladder reconstruction. 10% (vs 0 in prenatal) required vesicostomy in postnatal group (Clayton). Perhaps small advantage in spontaneous continence in prenatal closure (Carr, Clayton) The most clear data is regarding timing of postnatal closure. There are clear advantages in terms of upper tract health and bladder dynamics if closed within 72 hours but also an advantage in terms of bladder capacity and leak point pressure if closed within 24 hours. As additional techniques and experiences evolve for prenatal management, this will require updated review of literature.

One additional important consideration and one for which there is no literature, is the feasibility for all infants nationally and globally to have proactive urologic medical management that includes intermittent catheterization and serial urodynamics surveillance. Cost to family and access to specialized care are not something that we can presume is manageable for every infant. These considerations will make a health care guideline for proactive medical management difficult to mandate. Again, however, the breadth and the prospective nature of the Edelstein et al work is likely the most compelling that at least a baseline CMG is indicated to profile the bladder and guide early management.

Works to be cited (others reviewed but discounted):

Conservative:


Kaufmann et al. [44% UT changes, 10% vesicostomy]


Proactive:


[birth to 2 years medical therapy results in sl less renal damage and statistically less surgery for refractory UT changes; rec CIC and antichol from birth]


Kaefer M, Pabby A, Kelly M, et al. Improved bladder function after prophylactic treatment of the high risk neurogenic bladder in newborns with MM. J Urol 162: 1068-71, 1999 [Looked only at those with high risk urodyn and compared those started upon diagnosis vs those delayed. UT changes in 19% expectant and 0 proactive. 100 % on CIC due to nature of population. 2x risk of augmentation in the delayed/expectant group].


Other:


Routh JC, etal. Design and methodological considerations of the Centers for Disease Control and Prevention Urologic and Renal Protocol for the NG and young child with spina bifida. J Urol 196: 1728-1734, 2016 [this is included as it is mentioned above but there is no data. Published protocol]

**I decided to leave out papers that were purely related to technique or utility of CMG, as we know that there are issues and opinions.

Prenatal vs Postnatal:


Carr MC. Urological results after fetal MM repair in pre-MOMs trial patients at CHOP. Fetal DiagnosticTherapy 37: 211-218, 2015.