

Recommendations from the Hydrocephalus Association Transition Summit, February 2017

Primary responsibility Area	Hospitals, health systems, and practices	Professional societies 1/ 2	Hydrocephalus Association
Processes and infrastructure for transition and longitudinal care	<ol style="list-style-type: none"> 1. Incorporate the Six Core Elements of Health Care Transition into their existing care processes. 2. Provide appropriate resources to assist youth and their families through the HCT process. 3. Develop programs for HCT and longitudinal care for young adults with hydrocephalus, or if geographic and resource constraints prevent the development of such programs, develop relationships with other HCT and longitudinal care programs so that patients can receive appropriate care. 4. Ensure that all adults with hydrocephalus have access to a primary care medical home that has ready access to appropriate specialists to guide care management. 	<ol style="list-style-type: none"> 1. Support the development of clinical practice guidelines for hydrocephalus at all stages of life 2. Incorporate the Six Core Elements of Health Care Transition into clinical practice guidelines for patients with hydrocephalus, and encourage their adoption by pediatric and adult HCPs who provide care for patients with hydrocephalus 3. Promote the development of programs for health care transition and longitudinal care for youth with hydrocephalus throughout the United States and Canada, or, where this is not feasible, support the incorporation of youth with hydrocephalus into existing health care transition programs. 4. Develop a HCT readiness assessment, medical summary/transfer record, and self-care assessment for youth with hydrocephalus 	
Training		<u>Adult and pediatric neurosurgery and neurology</u> <ol style="list-style-type: none"> 1. Create learning objectives for pediatric and adult hydrocephalus within 	

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		<p>undergraduate medical education, and work with the AAMC to incorporate these objectives into the medical school curriculum nationally.</p> <ol style="list-style-type: none"> 2. Develop curricular requirements for residency training via the ACGME for the physiology, pathophysiology, and treatment of hydrocephalus, and for health care transition, and include these topics in self-assessment examinations 3. Include the topic of health care transition in board certification examinations. 4. Address the “hidden curriculum” that can create a culture within training and practice that adversely affects patients with hydrocephalus 5. Provide CME opportunities for hydrocephalus and health care transition 6. Work with primary care professional societies (e.g., AAP, AAFP, ACP) to create educational products that will help primary care providers to participate in the care of youth and adults with hydrocephalus <p><u>Nursing and social work</u></p> <ol style="list-style-type: none"> 1. The AANN should create a standard curriculum for hydrocephalus, and work with 	
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		<p>the American Association of Colleges of Nursing to incorporate the curriculum into undergraduate nursing education.</p> <p>2. The SSWLHC should encourage universities with schools of Social Work to include transition to adulthood education into healthcare-related curriculum.</p>	
Payment			<p>1. Advocate for reassessment of the RVUs of surgical and medical care for patients with hydrocephalus so that reimbursement is commensurate with the effort required to provide this high value care.</p> <p>2. Advocate for appropriate valuation of hydrocephalus treatment and longitudinal care in new payment models</p>
Insurance			<p>1. Advocate for the retention of existing legislative and regulatory provisions that allow children to remain on their parents' insurance plan in early adulthood, prohibit insurers from discriminating against persons with pre-existing conditions, prohibit annual and lifetime limits on insurance payments, and require out of pocket spending limits</p>
Research		<p>1. Promote the funding of research in population health, health</p>	<p>1. Encourage the pediatric research network (Hydrocephalus Clinical</p>

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		services, and health care economics of HCT and longitudinal care for youth with hydrocephalus, with the goal of providing data and economic models that can be used to assess the outcomes of different models of care.	Research Network, HCRN) and adult research network (Adult Hydrocephalus Clinical Research Network, AHCN) to define common data elements, and develop mechanisms for patients enrolled in the HCRN to be followed in the AHCN after the age of 18 so that a detailed picture of the health care services and outcomes across the lifespan can be developed and used to improve care.
Support and education of patients and families			<ol style="list-style-type: none"> 1. Develop and keep up-to-date a roster of clinics, programs and physicians who provide HCT and adult care in hydrocephalus in the United States and Canada. 2. Develop and make available resources for health care transition specific for hydrocephalus 3. Develop and disseminate information about health care transition for teenagers and young adults. 4. Promote the pursuit of an adult focused primary care medical home
Advocacy			<ol style="list-style-type: none"> 1. Work with medical specialty societies, nurses' organizations; hospital associations; national insurance associations; independent living associations; and disability rights groups to

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			develop an advocacy agenda for HCT that can be implemented at federal, state and regional levels.
Follow up			1. Convene a follow-up Transition Summit in about 2023

1/ Recommendations in the purview of professional societies in adult and pediatric neurosurgery and neurology are reflected in Williams et al (in press), Improving Health Care Transition and Longitudinal Care for Adolescents and Young Adults with Hydrocephalus: Report from the Hydrocephalus Association Transition Summit, *Journal of Neurosurgery*.