ONLINE ONLY

Supplemental material

Improving health care transition and longitudinal care for adolescents and young adults with hydrocephalus: report from the Hydrocephalus Association Transition Summit

Williams et al.

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The major goal of the Hydrocephalus Association (HA)’s Transition Summit is to raise a call to action by key stakeholders to address the need for transitional care for patients with hydrocephalus, by establishing a set of actions and measurable goals that can be reached within 5-10 years. Actions will be targeted to both systemic change, and development and adoption of best practices, with the overall objective of fostering the creation of effective transitional programs at multiple centers throughout the United States and Canada. The results of the Summit will be translated quickly into a White Paper.

Through the presentations, discussions, and breakout groups, the speakers and conference participants will address both the content and the relational aspects of creating a new ecosystem for transitional care in hydrocephalus, establish measurable outcomes, create sustainable collaborations, and establish processes for holding ourselves accountable to achieving this important goal.

Each of Plenary Sessions 2-7 will include a presentation followed by plenty of time for discussion. The afternoon of the second day will see the group break into smaller subgroups to discuss key priorities and actions, and come together again to develop a consensus.

Transition is a complex issue with many intertwined elements, and so we ask that you make every effort to attend, and actively participate in, every session of the Summit. The breakout groups and wrap-up session will be able to forge a common view only out of a shared understanding of all the facets of transition.

The Hydrocephalus Association and the Hydrocephalus Transition Summit Steering Committee are very grateful for the invaluable support of the Theodore J. Batterman Foundation, which made the Summit possible.
Friday February 17

7:30 am – 8:15 am  
Breakfast available, Metropole Room (Met Room)

8:15 am – 9:30 am  
Plenary Session 1  
INTRODUCTION: THE PROBLEM

Welcome  
Diana Gray  
Chief Executive Officer, Hydrocephalus Association

Hydrocephalus: Facts and Challenges  
Dr. Mark Hamilton  
Director, Adult Hydrocephalus Program, University of Calgary

A Patient’s Experience  
Olivia Maccoux  
Patient

Results of Patient and Parent Focus Groups  
Tessa van der Willigen  
Member, Hydrocephalus Association Board of Directors, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

Review of Agenda and Targeted Outcome  
Dr. Michael A. Williams  
Director, Adult and Transitional Hydrocephalus and CSF Disorders, Professor of Neurology and Neurological Surgery, University of Washington School of Medicine, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

9:30 am – 9:45 am  
BREAK

9:45 am – 11:15 am  
Plenary Session 2  
PROCESSES FOR TRANSITIONAL CARE: STATE OF THE ART

This session will lay out the principles that should guide transition, discuss its key dimensions, and review lessons from the literature as regards its processes.

Dr. Patience White  
Co-Director, Got Transition: The Center for Health Care Transition Improvement
11:15 am – 11:30 am
BREAK

11:30 am – 1:00 pm
Plenary Session 3
HEALTH CARE PROFESSIONALS FOR TRANSITIONAL CARE IN HYDROCEPHALUS: CURRENT STATE AND FUTURE NEEDS

This session will consider the availability of health care professionals (neurosurgeons, neurologists, primary care providers) to provide appropriate transitional care in hydrocephalus, and the forces that shape this, including training, the influence of practice environment, and the influence of payment systems.

Dr. David Wood
Chair, Department of Pediatrics, ETSU College of Medicine

Dr. Michael A. Williams
Director, Adult and Transitional Hydrocephalus and CSF Disorders, Professor of Neurology and Neurological Surgery, University of Washington School of Medicine, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

Dr. Richard Ellenbogen
Professor and Chairman, Department of Neurological Surgery, Seattle Children's Hospital

1:00 pm – 2:15 pm
LUNCH WITH PANEL Q&A

Moderator:
Dr. Michael A. Williams
Director, Adult and Transitional Hydrocephalus and CSF Disorders, Professor of Neurology and Neurological Surgery, University of Washington School of Medicine, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

Panel:
Jennifer Bechard, Education Manager, Hydrocephalus Association, Patient
Betsy Conyard, Parent
Sam Marks, Patient
Natalie Higashiyama, Parent
2:15 pm – 3:45 pm
Plenary Session 4
INFLUENCE OF HEALTH SYSTEMS, PAYERS, AND GOVERNMENTAL ORGANIZATIONS ON THE DEVELOPMENT OF TRANSITIONAL CARE

This session will consider the influence of systemic issues on the availability of transitional care and on patients' ability to access it. It will discuss challenges created by insurance availability and reimbursement rules, and risks and opportunities created by government initiatives in these areas.

Tessa van der Willigen
Member, Hydrocephalus Association Board of Directors, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

Dr. Nancy Fisher
Chief Medical Officer, Centers for Medicare and Medicaid Services, Seattle Regional Office

3:45 pm – 4:00 pm
BREAK

4:00 – 5:30 pm
Plenary Session 5
STRUCTURAL/CLINIC MODELS FOR TRANSITIONAL CARE

This session will discuss the range of structured intervention models (e.g., transition clinics in the pediatric or adult system, joint clinics, “lifetime” clinics), their impact, and how to determine the appropriate scope of intervention.

Dr. Patience White
Co-Director, Got Transition: The Center for Health Care Transition Improvement

Dr. Mark Hamilton
Director, Adult Hydrocephalus Program, University of Calgary

Dr. Susan Hunt
Assistant Professor of Medicine and Pediatrics, and Director of Transitional Care, University of Washington
5:30 pm – 5:40 pm
CLOSING REMARKS

Dr. Michael A. Williams
Director, Adult and Transitional Hydrocephalus and CSF Disorders, Professor of Neurology and Neurological Surgery, University of Washington School of Medicine, and Co-Chair, Hydrocephalus Transition Summit Steering Committee

Saturday February 18

7:45 am – 8:45 am
Breakfast available, Metropole Room (Met Room)

8:45 am – 10:15 am
Plenary Session 6
PLANNING FOR TRANSITION: PREPARING YOUTH AND FAMILIES FOR ADULT HEALTH CARE

This session will discuss best practices in the preparation phase of transition, including available tools, templates, and informational materials.

Dr. David Wood
Chair, Department of Pediatrics, ETSU College of Medicine

10:15 am – 10:45 am
BREAK

10:45 am – 12:15 pm
Plenary Session 7
INTEGRATING THE YOUNG ADULT INTO ADULT CARE

This session will discuss best practices in the transfer and integration of the patient into the adult health care system, including the transfer of medical information to the adult provider.

Dr. Cecily Betz
Professor of Pediatrics, Keck School of Medicine, University of Southern California

12:15 pm – 1:30 pm
LUNCH
1:30 pm – 3:00 pm

Breakout Sessions

PRIORITIES, MEASURABLE GOALS, STRATEGIES, AND ACCOUNTABILITY

Participants will be assigned to one of four breakout groups to discuss the themes that emerged from the Plenary Sessions and to propose actions and accountabilities in the areas of infrastructure (including identification of best practices), payment, training, research, and advocacy. Breakout groups will be intentionally composed of participants with different kinds of expertise and perspectives, to encourage creativity and to ensure that all angles of an issue are thought through. The groups will focus respectively on:

1. Health care professionals (HCP) and HCP professional societies

   Facilitators:
   **Dr. Larry Brown**, Associate Professor of Neurology and Pediatrics, Children’s Hospital of Philadelphia, and Child Neurology Foundation
   **Dr. Mark Hamilton**, Director, Adult Hydrocephalus Program, University of Calgary

2. Payment issues

   Facilitators:
   **Dr. Bruce Kaufman**, Professor of Neurosurgery and Chief of Pediatric Neurosurgery, Medical College of Wisconsin, Children’s Hospital of Wisconsin
   **John Lawrence**, Member, Hydrocephalus Association Board of Directors

3. Implementation of transitional care models and practices

   Facilitators:
   **Cathy Cartwright**, Director of Advanced Professional Practice and Pediatric Clinical Nurse Specialist, Neurosurgery, Children’s Mercy Hospital, Kansas City
   **Dr. Mandeep Tamber**, Pediatric Neurosurgeon, University of Pittsburgh School of Medicine/Children's Hospital of Pittsburgh

4. Preparing and engaging patients and families

   Facilitators:
   **Terri Hickam**, Transition Program Manager, Children’s Mercy Hospital, Kansas City, and Society for Social Work Leadership in Healthcare
   **Dr. Marion L. (Jack) Walker**, Emeritus Professor of Neurosurgery, University of Utah
3:30 pm – 5:00 pm

WRAP-UP

The full group will hear reports from the breakout groups and seek a consensus on the outline of an action plan. Next steps, including accountabilities, will be formulated for finalization and dissemination of the action plan.

Moderators:

Dr. Michael A. Williams
Tessa van der Willigen
Co-Chairs, Hydrocephalus Transition Summit Steering Committee