



Hydrocephalus Association
10th National Conference on Hydrocephalus

June 19-22, 2008
Park City, Utah
The Canyons

Preliminary Conference Agenda

Thursday 6/19/2008

12:00 - 8:00pm **Registration**

Thursday 6/19/08

4:00-4:15 **Welcome**

4:15-5:45 **Session I**

Anatomy & Physiology of Hydrocephalus (Video of Gel Brain Surgery Demo)

Neuroscientists are your guides in this hands-on tour of brain anatomy and physiology complete with plastic and gelatin models.

By the end of this session, participants will have a general understanding of the structure and function of the parts of the brain that are most affected by hydrocephalus, including a better knowledge of what can be seen on CT scans and MRIs, as well as a "feel" for how a shunt is placed into the brain. A simple, straight-forward slide presentation and discussion will serve as a "primer" for the anatomy and physiology; this will be accompanied by your own "surgery" for placing shunts into life-size gelatin brains and draining cerebrospinal fluid.

Intended Audience: All ages and stages.

7:30-9:30 **Dessert Reception**

All registered attendees

Friday 6/20/08

8:00 - 5:00 **Registration open all day**

Friday 6/20/08

8:00-8:15 **Welcome**

8:15-9:15 **Scientific Keynote (Robert Pudenz lectureship sponsored by Rudi Schulte Research Institute)**

9:15 - 11:00 **Session II**

Interpersonal Connection Sessions

A.1 **Fathers**

A.2 **Mothers**

A.3 **Adults treated in Childhood**

A.4 **Teens with Hydrocephalus**

A.5 **Adults diagnosed in young and middle age**

A.6 **Adults with Normal Pressure Hydrocephalus (NPH)**

A.7 **Siblings**

A.8 **Spouses**

11:15 -12:15 **Session III**

B. **Families with Young Children**

This session will give basic information about medical treatment and follow-up care of children with hydrocephalus. It will also address what to expect of your doctor and the hospital.

Intended Audience: Parents of infants and young children

C. **Parents of Children with Complex Hydrocephalus or Multiple shunts**

About 15% of people with hydrocephalus require more than one shunt or procedure to bring multiple compartments into communication. Some people, including those with Dandy Walker, may have a cyst

that requires fenestration or other surgical management. You may have heard the term "Loculated ventricles" or "multi-Loculated hydrocephalus" and want to understand more about it. This session will touch on these different complex forms of hydrocephalus and the pros and cons of multiple shunt systems and endoscopic management. By the end of this session the participants should be able to differentiate between the different forms of complex hydrocephalus and the various treatment options available.

Intended Audience: Patients with multiple shunts or complex hydrocephalus, and their families.

D. Teens and Families of Teens

This session will address how things can suddenly change during adolescence e.g.: small ventricles; eliminating shunts; regular teenage concerns: sports, social issues, driving, sexuality By the end of this session, participants will be able to identify high risk behavior for patients with shunts and understand relevant literature regarding the topic; Anticipate the needs of the adolescent in social development; Identify resources and support in the community; Understand and anticipate medical changes and needs.

Intended Audience: Teens and their parents.

E. Adults Who Were Treated in Childhood, Including First Generation.

The session will address issues of living with hydrocephalus since childhood, including subtle signs of shunt malfunction, possible over-/under-drainage problems, long-term complications, as well as strategies for documenting patterns to aid in communication with medical professionals.

Intended Audience: Persons with hydrocephalus ages 18 and older who were diagnosed in childhood.

F. Adults Diagnosed in Young and Middle Age

This session will discuss the symptoms, diagnosis, treatment options and follow-up care of people who were diagnosed with hydrocephalus during their adult years (also known as adult-acquired or adult-diagnosed hydrocephalus). Learning Objectives: By the end of this session, participants will be able to list the 4 primary symptoms of the syndrome of hydrocephalus in young and middle aged adults (SHYMA); describe 2 reasons that SHYMA is difficult to diagnose; and explain why SHYMA influences patients' lives different from NPH.

Intended Audience: Persons with hydrocephalus who first diagnosed and treated between ages 18 and 65

G. Adults with Normal Pressure Hydrocephalus (NPH)

This session will discuss diagnostic protocols, shunting procedures, possible complications and risks, long-term outcomes and care options for people with NPH.

Intended Audience: Persons with hydrocephalus diagnosed over age 65 and their families.

12:15-1:15 **LUNCH - Served in Room. Time for participants to compose questions**

1:15-2:15 **Session IV**

H. Families with young Children: Question and Answer with Doctors

This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.

Intended Audience: Parents of infants and children under 12

I. Parents of Children with Complex Hydrocephalus: Question and Answer With Doctors

This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.

Intended Audience: Parents of children

J. Teens and Families of Teens

This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.

Intended Audience: Teens and their parents

K. Adults Who were Treated in Childhood: Question and Answer with Doctors

This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.

Intended Audience: Persons with hydrocephalus ages 18 and older who were diagnosed in childhood

- L. **Adults Diagnosed in Young and Middle Age: Question and Answer with Doctors**
This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.
Intended Audience: Persons with hydrocephalus diagnosed and treated between ages 18 and 65 and their families
- M. **Adults Diagnosed with Normal Pressure Hydrocephalus: Question and Answer with Doctors**
This session is an opportunity for you and your peers in a small group to ask doctors and nurses questions about hydrocephalus. This session is not intended for persons to obtain individualized medical advice or consultation.
Intended Audience: Persons with hydrocephalus diagnosed over age 65 and their families. Marvin Bergsneider,

Friday 6/20/08

2:15-2:45 **BREAK**

2:45-4:00 **Session V**

- N. **Clinical Trials and Basic Research**
Researchers need your permission to learn from you. This session will discuss what it means to participate in a clinical trial and why it is important.
By the end of this session, participants will be more informed about how basic science experiments translate into clinical research, what clinical studies of hydrocephalus are currently being conducted and which ones are most likely to be started in the near future, and how you and/or your child could contribute to these important studies.
Intended Audience: All ages and stages
- O. **Endoscopy: ETV, Loculated Ventricles, Distal Catheter Placement with Peritoneal Scarring, etc.**
Shunt malfunctions are a fact of life for people with hydrocephalus. This session will discuss strategies for dealing with shunt malfunctions, including loculated ventricles, use of ET, distal complications and situations when "the scans look fine." By the end of this session, participants will be able to identify options for patients with hydrocephalus outside of standard ventriculoperitoneal shunting...i.e. "How to think outside the shunt"....
Intended Audience: All ages and stage.
- P. **Keeping Family Together with a Chronically Ill Child**
Having a loved family member who lives with a chronic medical condition can add stress and overwhelming emotional distress on a family and marriage.
At end of this session participants will be able to identify factors that add stress to family and marriage when living with a member who has a chronic medical condition, identify measures that can reduce stress in families and better evaluate stress within their own families and marriage.
Intended Audience: Parents, spouses and caregivers, no children under 18 please.
- Q. **Continuation of Care as You Move from Pediatric to Adult Care.**
Transition from pediatric to adult-centered care is the objective for every child. This session will discuss the process from both the patient's and medical professional's prospective and present strategies to prepare both the child and the parent for the transition.
Intended Audience: Teens and young adults with hydrocephalus and their families.
- R. **The Role of Neuropsychology in Assessing and Managing Learning Challenges**
This session will address assessing learning strengths and weaknesses in order to develop specific learning adaptation and accommodations to facilitate the educational experience, reduce stress, and optimize educational outcome. Participants will be able to understand the specific characteristics of NLD better understand the role of neuropsychology and understand the evaluation process and be able to identify resources available for NLD as well as become familiar with specific strategies of potential benefit.
Intended Audience: Parents of children with hydrocephalus.

S. **Second Opinions: Your Rights and Responsibilities**

Michael A. Williams, MD, will share important information about how and when to seek second opinions and the role of the neurologist in hydrocephalus treatment.

By the end of this session, participants will be able to describe 2 advantages and disadvantages of obtaining a 2nd opinion; list 2-3 reasonable and unreasonable expectations of 2nd opinions; and identify 2 major differences between the roles of neurologists and neurosurgeons in caring for patients with hydrocephalus.

Intended Audience: All ages and stages.

4:00-4:30 **BREAK**

4:30-5:30 **Creative Keynote, Sherman Alexie**

Group Photographs

Participants Dinner on their own

Saturday 6/21/08

8:00-9:30 **How Shunts Work**

Doctors and representatives from different shunt manufacturers will work together to provide an overview of shunt technology. They will try to help you understand why a doctor chooses a particular shunt for a particular situation.

Intended Audience: All ages and stages

9:30-9:45 **BREAK**

9:45-11:00 **Session VI**

T. **Letting Go and Moving on. For Parents of Teens and Young Adults.**

It's an age-old struggle complicated by chronic condition. Parents, young adults and the first generation of people shunted for hydrocephalus will discuss their fears and frustrations and share their strategies for establishing and maintaining independence while setting up appropriate safety nets among friends and family.

Intended Audience: Teens and young adults with hydrocephalus and their families

U. **Slit Ventricles vs. Slit Ventricle Syndrome**

Very Small or slit ventricles are a common finding in children shunted for a long period of time. It occurs in approximately 60% of patients shunted in childhood. This session will discuss the implications of having slit ventricles, the types of difficulty that may occur and possible treatment options. By the end of this session participants should have a better understanding of slit ventricles and the treatment options.

Intended Audience: Persons with hydrocephalus diagnosed in infancy and childhood and their families

V. **Shunt vs. ETV**

Endoscopic Third Ventriculostomy (ETV) is a promising alternative treatment to shunting for some types of hydrocephalus. This session will discuss the procedure, as well as criteria for patient selection, benefits and possible risks.

Learning Objectives: By the end of this session, participants will be able to cite relevant literature for ETV, understand clinical indications, surgical technique and risk/benefit ratio.

Intended Audience: All ages and stages

W. **Prospective Trial Data Collection. HCRN**

X. **How to Talk About Difference, Disability, Loneliness with Your Kids and How to Deal with Those Feelings in Yourself.**

Families often avoid talking directly about differences to avoid emphasizing them, but this failure to discuss these issues may actually accentuate the differences. Learning Objectives: At end of this session participants will be able to Describe ways to improve communication with children; Identify common fears and concerns of children with chronic medical problems and Better attend to nonverbal messages in interactions with children

Intended Audience: Parents of children with hydrocephalus

Y. **Subtle Discrimination: Ways to Inform Teachers and Others without Inviting This.** *Panel*

11:00-11:15 **BREAK**

Saturday 6/21/08

11:15-12:30 **Session VII**

Z. **New Insights into the Role of Pulsatility in Hydrocephalus**

A neurosurgeon who treats hydrocephalus and a basic scientist will explain the importance of normal and abnormal pulsations within the brain.

Intended Audience: All ages and stages

AA. **Unwanted Medical Outcomes (The Difference Between Malpractice and an Unwanted Outcome)**

Learning Objectives: By the end of this session, participants will have a better understanding of a relatively new mechanism that accompanies (and may cause) hydrocephalus. This mechanism, which involves the to-and-fro movement of cerebrospinal fluid and blood, is one of the "hot topics" of current clinical and basic research, and may change the diagnosis and treatment for hydrocephalus in the future.

Intended Audience: All ages and stages

BB. **Endocrinology: Precocious Puberty and other issues**

CC. **Shunt Infections (Include Abdominal Pseudocysts)**

Intended Audience: All ages and stages

DD. **The Current State of Healthcare in the US**

Intended Audience: All ages and stages

EE. **Headaches and Hydrocephalus**

12:30-1:45 **LUNCH**

1:45- 3:00 **Session VIII**

FF. **Parenting a Child with Multiple Disabilities**

Some children with hydrocephalus have a multitude of other medical problems such as spina bifida, loss of vision, cerebral palsy, developmental disabilities or mental retardation. This session will validate the challenges of parenting a child with multiple disabilities or mental retardation. This session will validate the challenges of parenting a child with multiple disabilities and discuss the ongoing medical issues, including coordination of care and planning for the future.

Intended Audience: Parents of children of any age with multiple disabilities

GG. **Employment**

This Session will address questions like: "How much information do I share and who do I share it with?" and "What should I tell my supervisor, co-workers, and people who work for me?" This session will also discuss rights and reasonable accommodations under the Americans with Disabilities Act (ADA) for people with hydrocephalus who are working or looking for work. Learning Objective: At the end of this session, participants will be able to feel more comfortable about what and with whom information should be shared at their respective employers.

HH. **Talking about and Dealing with Death (Including When and Why it Might Occur in Relation to Hydrocephalus)**

Persons with hydrocephalus at any age can die, sometimes as a result of hydrocephalus or its complications, and sometimes as a result of other illnesses or conditions. This session will help participants learn how to prepare for the possibility of dying, including the selection of a person to make decisions for you if you cannot make them for yourself, and the preparation of a living will. Palliative care and curative care approaches will be discussed.

Learning Objectives: By the end of this session, participants will be able to identify 2 resources for hospice, palliative care, advance care planning and end-of-life decisions for children or adults as appropriate.

Intended Audience: All ages and stages

II. **Enrolling Teacher Accommodation: Individual Education Plans for Children in School.**

Federal law guarantees all children a free education in the least restrictive environment. This workshop will discuss the Individualized Education Plan (IEP) process as well as the Individuals with Disabilities Education Act (IDEA) and Section 504. Learn strategies to advocate if your child falls through the cracks or is denied services for which they are eligible to get their learning needs met in the public school system.

Intended Audience: Parents of school-age children

JJ. **Pregnancy in Women with Hydrocephalus**

This session will discuss the ongoing study on maternal shunt dependency with the goal of improving treatment for shunt-dependent expectant mothers.

Intended Audience: Women with hydrocephalus and their spouses and partners

KK. **MyHIN - Electronic Personal Health Record for Hydrocephalus**

Tired of lugging CT, MRI scans and medical records around? Afraid of getting caught without these critical documents? Come learn about an online medical record tailored for people with hydrocephalus.

Intended Audience: All ages and stages

3:00-3:30 **BREAK**

3:30-4:30 **Research Advocacy & Awareness - Progress in the Public and Private Sector - Climbing our Hydrocephalus Everest**

Professionals who conduct studies and parents who raise funds to support these studies will discuss the obstacles facing hydrocephalus research, and most importantly the recent progress that has been made with the National Institutes of Health, private foundations and local support groups. Learning Objectives: By the end of this session, participants will know what landmark advances have been made to support hydrocephalus research at all levels, what still needs to be done, and how you can be involved in this important process.

Intended Audience: All ages and stages Curt Stewart - BrainChild, John Kestle, MD - HCRN, Dianne Kean - STARS, Pat McAllister, PhD - NIH & Congress

4:40-5:15 **Inspirational Keynote: Climbing Everest**

Douglas Brockmeyer, MD

6:00 - 9:30 **Dinner Dance**

Sunday 6/22/08

Session IX

Repeats of Favorite Sessions (Selected by Participant Votes)

8:30-9:45 **Anatomy & Physiology of Hydrocephalus (video of gel brain surgery demo)**

Neuroscientists are your guides in this hands-on tour of brain anatomy and physiology complete with plastic and gelatin models.

Learning Objectives: By the end of this session, participants will have a general understanding of the structure and function of the parts of the brain that are most affected by hydrocephalus, including a better knowledge of what can be seen on CT scans and MRIs, as well as a "feel" for how a shunt is placed into the brain. A simple, straight-forward slide presentation and discussion will serve as a "primer" for the anatomy and physiology; this will be accompanied by your own "surgery" for placing shunts into life-size gelatin brains and draining cerebrospinal fluid.

Intended Audience: All ages and stages

9:45-10:15 **BREAK**

10:15-12:00 **Intergenerational Panel and wrap-up**