



*Getting to the Heart of Hydrocephalus*

12th National Conference on Hydrocephalus



## Conference Program

June 27 - July 1, 2012  
Bethesda North Marriott  
Bethesda, MD

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## Conference Medical Chairs



**Marion L. Walker, MD**

Professor of Neurological Surgery  
 Department of Neurological Surgery  
 Division of Pediatric Neurosurgery  
 University of Utah Health Sciences Center  
 Primary Children's Medical Center



**Michael A. Williams, MD**

Medical Director, Sandra and Malcolm  
 Berman Brain and Spine Institute  
 Director, Adult Hydrocephalus Center, Sinai  
 Hospital Co-Director, Center for Gait and  
 Mobility, Sinai Hospital of Baltimore

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# CONFERENCE FACULTY

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Krieger Eye Institute At Sinai  
Baltimore, MD

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Debby Buffa  
Board Member  
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Dave Carl, MSW  
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Lori Day, Ph.D.  
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Hydrocephalus Association Founder  
San Francisco, CA

Russell Fudge  
Board Member and Founder  
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FRCSC  
The Hospital for Sick Children  
University of Toronto  
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Director, National Institute for  
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John A. Lawrence  
Chief of Staff  
Democratic Leader, U.S. House of Rep-  
resentatives  
Washington, DC

Leanne Lintula  
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Mark Luciano, MD, Ph.D., FACS  
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Dawn Mancuso, MAM, CAE, FASAE  
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Janet Miller  
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Jill Morris, Ph.D.  
Program Director, National Institute for  
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Joseph Piatt, MD, FAAP  
A I duPont Hospital for Children  
Wilmington, DE

Dorothy Poppe  
Chiari and Syringomyelia Foundation  
Staten Island, NY

Harold L. Rekate, MD, FACS, FAAP  
Chiari Institute  
Northshore University Hospital  
Great Neck, NY

Jay Riva-Cambrin, MD  
University of Utah and Primary  
Children's Medical Center  
Park City, UT

Larry Rivkin  
Rivkin & Rivkin, LLC  
Lincolnshire, IL

Amy Rosenbaum  
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Robin Wilson, MD, Ph.D.  
The Sandra and Malcolm Berman  
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Baltimore, MD

Andrew Zabel, Ph.D., ABPP  
Kennedy Krieger Institute  
Baltimore, MD



## GENERAL INFORMATION

### **Children:**

Infants and young children are welcome in the sessions as long as they remain quiet and do not disturb other attendees. If your child becomes disruptive or irritable, we must request that you leave the room. We are offering a Kids Camp for children ages 3-11. Please inquire at the registration table for more information.

### **Breakfast / Lunch:**

Complimentary continental breakfast will be served Thursday - Sunday in the Ballroom Foyer near the Registration Desk. Lunch will be served Thursday (for Advocacy Day Participants ONLY), Friday and Saturday for all registered attendees. Lunch on Thursday will be served on the busses. Lunch on Friday and Saturday will be in the General Session Room - Salons D&E.

### **Advocacy Day:**

***Climbing Capitol Hill for a Cure!*** Join us on a special day of action on Thursday, June 28<sup>th</sup>. Training sessions will start on Wednesday June 27<sup>th</sup> with Ms. Judy Schneider and Thursday morning with John Lawrence and Amy Rosenbaum. We will be going to visit with our representatives on Thursday afternoon. Please go to page 9 for a detailed schedule.

### **Family Dinner Dance/Talent Show:**

The Family Dinner Dance will take place in Salons D & E on Saturday from 6:00pm - 9:30pm. Dinner will be served at 6:00pm, followed by the Talent Show from 7pm - 8pm. Dancing and entertainment will go until 9:30pm. Dinner is free for conference registrants. For guests that have not pre-purchased tickets, please inquire at the Registration Desk for availability.

### **Talent Show:**

The Hydrocephalus Association Conference Talent Show will begin at 7:00pm on Saturday night. This event is open to all conference attendees. If you are interested in signing up to show off your talent - please visit the Registration Desk for more information.

### **Exhibits:**

Our Conference Sponsors will host exhibit tables. Many have trained staff to answer your questions about shunts and neurosurgical products. We encourage you to visit the exhibits. When you do, please say thanks. Their sponsorship helps us keep the conference fees low.

### **Conference Evaluations:**

The session evaluations and the overall conference evaluation are located on pages 34-39. Once you have completed the evaluations please tear them out of the program and hand them in at the registration desk.

### **Bulletin Board:**

There is a message board near the Registration Desk. If you who would like to make connections with others, we encourage you to post a message.

### **Conference Souvenirs:**

Hydrocephalus Association t-shirts and caps are for sale in the Registration Area. Payment is accepted by either cash or check.

**Join Us!** If you are not currently a supporter of the Hydrocephalus Association, contribution forms are available at the Registration Desk. Our organization is sustained by our highly dedicated community. We hope you will take this opportunity to join our community of generous champions.

# CONFERENCE SCHEDULE

**Wednesday, June 27, 2012**

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12:00 p.m. - 5:00 p.m.    **Conference Registration Open**    *Grand Ballroom Foyer*

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3:00 p.m. - 3:15 p.m.    **Conference Welcome**    *Grand Ballroom Salon E*

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***Presenters:***

- ◆ Paul Gross, Board Chairman, Hydrocephalus Association
- ◆ Dawn Mancuso, MAM, CAE, FASAE, CEO, Hydrocephalus Association
- ◆ Marion Walker, MD, Conference Medical Co-Chair
- ◆ Michael Williams, MD, Conference Medical Co-Chair

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3:15 p.m. - 4:15 p.m.    **Anatomy and Physiology of Hydrocephalus**    *Grand Ballroom Salon E*

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***Presenter:***

- ◆ J. Pat McAllister, Ph.D.

A primer of brain anatomy and physiology related specifically to hydrocephalus. By the end of this session, participants will have a general understanding of the vocabulary used in treating hydrocephalus, how cerebrospinal fluid is made and how it flows out of the brain to be absorbed, what parts of the brain are most affected by hydrocephalus and how they produce neurological deficits, and what can be seen on CT scans and MRIs. Following the lecture and throughout the meeting participants will have an opportunity to experience "surgery" by placing shunts into life-size brain models and draining cerebrospinal fluid.

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4:30 p.m. - 5:15 p.m.    **Advocacy Part I:  
Getting to the Heart of Congress**    *Grand Ballroom Salon E*

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***Presenter:***

- ◆ Judy Schneider

Ms. Schneider is well known on Capitol Hill by members of Congress, staff and lobbyists as THE person to go to for information on numerous topics including House, Senate and Committee Procedure. In this session you will learn the secrets of how Congress works and how to get your message across to your representatives.

# CONFERENCE SCHEDULE

**Thursday, June 28, 2012**

7:00 a.m. - 5:00 p.m. **Conference Registration Open** *Grand Ballroom Foyer*

7:00 a.m. - 8:00 a.m. **Continental Breakfast** *Grand Ballroom Foyer*

8:00 a.m. - 9:45 a.m. **Advocacy Part II:  
Climbing Capitol Hill for a Cure** *Grand Ballroom Salons D&E*

**Presenters:**

- ◆ Amy Rosenblum
- ◆ John Lawrence

This session will provide an overview of strategies for approaching your state and federal representatives. We will focus on planning successful in-person visits to legislators to raise awareness and garner resources for hydrocephalus

10:00 a.m. - 11:15 a.m. **Interpersonal Connection Sessions**

A time to connect and share openly with peers in a safe, confidential setting

<u>Session</u>	<u>Location</u>
Fathers of children birth to 4 years old living with Hydrocephalus	Salon A
Fathers of children 5 to 12 years old living with Hydrocephalus	Salon A
Fathers of teenagers 13 to 18 years old living with Hydrocephalus	Salon A
Fathers of young adults 19 to 30 years old living with Hydrocephalus	Salon A
Fathers of adults 30 years and older living with Hydrocephalus	Salon A
Adults treated in infancy and childhood 19 years and older living with Hydrocephalus	Salon B
Adults diagnosed in young and middle age living with Hydrocephalus	Salon B
Adults with Normal Pressure Hydrocephalus (NPH)	Salon B
Mothers of children birth to 4 years old living with Hydrocephalus	Salon D/E
Mothers of children 5 to 12 years old living with Hydrocephalus	Salon D/E
Mothers of teenagers 13 to 18 years old living with Hydrocephalus	Salon D/E
Mothers of young adults 19 to 30 years old living with Hydrocephalus	Salon D/E
Mothers of adults 30 years and older living with Hydrocephalus	Salon D/E

**Interpersonal Connection Sessions Continued** ➡

# CONFERENCE SCHEDULE

**Thursday, June 28, 2012**

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10:00 a.m. - 11:15 a.m. **Interpersonal Connection Sessions continued**

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A time to connect and share openly with peers in a safe, confidential setting

<u>Session</u>	<u>Location</u>
Teenagers 12 to 18 years old living with Hydrocephalus	Foyer Area
Siblings of individuals living with Hydrocephalus- 12-18	Foyer Area
Siblings of individuals living with Hydrocephalus 19 and older	Foyer Area
Spouses and partners of individuals living with Hydrocephalus	Salon C
Grandparents of individuals living with Hydrocephalus	Salon C

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11:30 a.m. - 7:30 p.m. **Advocacy Day in Washington, DC: Climbing Capitol Hill for a Cure!**

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11:30 a.m. - 12:00 p.m.	Board busses at the Marriott
12:00 p.m. - 12:15 p.m.	Busses depart the Marriott - lunch served on the busses
1:00 p.m. - 1:30 p.m.	Arrive in Washington D.C.
1:00 p.m. - 4:00 p.m.	Meetings with Legislators

**4:30 p.m. - 6:00 p.m**



**Congressional Welcome Reception and Public Service Awards (Room HC-5)**

6:30 p.m.	Board busses back to the Bethesda North Marriott
7:30 p.m.	Arrive back to the Bethesda North Marriott

# CONFERENCE SCHEDULE

**Friday, June 29, 2012**

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7:00 a.m. - 5:00 p.m.      **Conference Registration Open**      *Grand Ballroom Foyer*

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7:00 a.m. - 7:50 a.m.      **Continental Breakfast**      *Grand Ballroom Foyer*

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7:50 a.m. - 9:30 a.m.      **Scientific Keynote:**      *Grand Ballroom Salons D&E*  
**Robert Pudenz Lectureship**  
*Sponsored by: Rudi Schulte Research Institute*

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**Scientific Keynote Speaker:**

- ◆ Story Landis, Ph.D.

NIH 101: Dr. Landis will be discussing the role of the NIH in Disease Research

**Scientific Presenters:**

- ◆ John Kestle, MD
- ◆ Jay Riva-Cambrin, MD
- ◆ J. Pat McAllister, Ph.D.

Moderated by: Gordon McComb, MD

The Rudi Schulte Research Institute, a not-for-profit private operating foundation established in 1974 by Rudi Schulte, conducts studies to elucidate and seek improved treatments for hydrocephalus and other neurological disorders. Dr. Robert Pudenz, a long-time board member of the Institute, passed away in 1998. The Robert Pudenz Lectureship was established in 1999 to acknowledge Dr. Pudenz's work in the area of hydrocephalus and his overall contribution to the advances made in the diagnosis and treatment of pediatric neurological diseases.

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9:45 a.m. - 11:00 a.m.      **Breakout Sessions: 100 Series**

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**101 Families with Young Children Living with Hydrocephalus**

*Intended Audience: Parents of Young Children*

**Joseph Piatt, MD**

**Location: Salon F**

*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 the doctor and the hospital.*

**102 Parents of Children with Complex Hydrocephalus and/or Multiple Shunts**

*Intended Audience: Parents*

**Marion Walker, MD**

**Location: Brookside B**

*This session will discuss management of patients with Dandy Walker malformations, multi-loculated ventricles and patients with multiple shunts. It is intended for patients and/or parents of patients with one or more of these conditions.*

# CONFERENCE SCHEDULE

**Friday, June 29, 2012**

## **103 Teens and Families of Teens**

*Intended Audience: Teens and Families of Teens*

**Jay Riva-Cambrin, MD**

**Location: Salon A**

*Teens with hydrocephalus and their families face many changes during adolescence, including small ventricles and possible elimination of shunts, as well as common teenage concerns such as playing or participating in sports, social issues, driving, and sexuality. By the end of this session participants will be able to identify high-risk behaviors for teens 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, and understand and anticipate medical changes and needs.*

## **104 Adults Who Were Treated in Childhood, Including First Generation**

*Intended Audience: Adults with Congenital Hydrocephalus*

**Harold Rekate, MD**

**Location: Salon B**

*The session will address issues of living with hydrocephalus since childhood, including the subtle signs of shunt malfunction, overdrainage or underdrainage problems, and long-term complications. It will also provide strategies for documenting patterns to aid in communication with medical professionals.*

## **105 Adults Diagnosed in Young and Middle Age (SHYMA)**

*Intended Audience: Adults diagnosed in Young and Middle Age and their Families (SHYMA)*

**Mark Luciano, MD, Ph.D.**

**Location: Salon C**

*This session will discuss the symptoms, diagnosis, treatment options and follow-up care of people diagnosed with hydrocephalus during their adult years.*

## **106 Adults and Their Families Affected by Normal Pressure Hydrocephalus (NPH)**

*Intended Audience: Adults with Normal Pressure Hydrocephalus (NPH)*

**Robin Wilson, MD, Ph.D.**

**Location: Brookside A**

*Attendees will learn about the history, signs, diagnostic evaluation, and treatment of NPH. Ample time will be given for questions and answers.*

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11:00 a.m. - 11:30 a.m.

**Coffee Break**

**Exhibit Area**

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# CONFERENCE SCHEDULE

Friday, June 29, 2012

11:30 a.m. - 12:45 p.m.

Breakout Sessions: 200 Series

## 201 Selecting Patients for Endoscopic Third Ventriculostomy (ETV)

*Intended Audience: All ages (not intended for NPH)*

**Abhaya Kulkarni, MD**

**Location: Salon F**

*Endoscopic third ventriculostomy (ETV) is a promising alternative treatment to shunting available for some types of hydrocephalus. This session will discuss the procedure, criteria for patient selection, and the procedure's benefits and possible risks. By the end of this session, participants will be able to cite relevant literature for ETV and understand clinical indications for the procedure, the surgical technique used, and the risks and benefits associated with the procedure.*

## 202 Neuro-Urology

*Intended Audience: NPH*

**David Gordon, MD**

**Location: Brookside B**

*Incontinence and poor bladder control are distressing problems often associated with hydrocephalus. This session will discuss the relationship that hydrocephalus has with urinary incontinence and neurogenic bladder (i.e., impaired bladder control resulting from injury or disease of the brain, spinal cord or peripheral nerves). The session will also address diagnostic techniques and treatment options such as Pudendal Nerve Conduction Studies and Lower Urinary Tract Botox Injections.*

## 203 Chiari and Syringomyelia (as it relates to Hydrocephalus)

*Intended Audience: All ages (not intended for NPH)*

**Mark Luciano, MD, Ph.D., and Dorothy Poppe**

**Location: Brookside A**

*Dr. Luciano will discuss situations in which Chiari malformation is seen in patients with hydrocephalus. When both conditions occur at the same time, symptoms may be confused and the treatment may vary. Do both need to be treated? Ms. Poppe will present on Chiari & Syringomyelia Foundation's (CSF) mission which will include related disorders and a summary of educational and support resources available to the hydrocephalus community*

## 204 Driving and Hydrocephalus

*Intended Audience: Teens and Adults*

**Jan Cyre, OT**

**Location: Salon B**

*Session objectives are:*

- *Participants will be able to describe the role and procedures of a driving evaluation program for varied medical issues and conditions*
- *Participants will be able to understand the motor vehicle administration, legal and liability issues of driving following medical changes*

# CONFERENCE SCHEDULE

Friday, June 29, 2012

11:30 a.m. - 12:45 p.m.

**Breakout Sessions: 200 Series continued**

## **205 Intracranial Hypertension (Pseudo Tumor Cerebri) and Ophthalmology**

*Intended Audience: All*

**Michael Altman, MD**

**Location: Salon C**

*Intracranial Hypertension (otherwise known as Pseudotumor Cerebri) is a condition of increased intracranial pressure (ICP) with symptoms that include headaches, visual loss and double vision. In common with hydrocephalus, the pressure in the brain is raised. Some of the symptoms and treatment options are quite similar to those of hydrocephalus, so there is some overlap between these conditions. In this session, Dr. Altman will discuss Pseudotumor Cerebri, its causes, diagnosis, and treatment.*

## **206 Transition of Care: The Challenges for Teens and Young Adults**

*Intended Audience: Parents, Teens and Young Adults*

**Harold Rekate, MD and Debby Buffa**

**Location: Salon A**

*This informative breakout session will encourage participants to ask questions about their transition issues, and participants will be given interesting topics to explore regarding transition.*

12:45 p.m. - 1:45 p.m.

**Luncheon Address**

**Public Funding Trends in Hydrocephalus Research**

**Grand Ballroom Salons D&E**

### **Presenters:**

- ◆ Paul Gross, Board Chairman, Hydrocephalus Association
- ◆ Jill Morris, Ph.D., Program Director, NINDS
- ◆ James Spence, U.S. Army Veteran

1:45 p.m. - 3:00 p.m.

**Breakout Sessions: 300 Series**

## **301 Insurance, SSI, Medicaid, Medicare**

*Intended Audience: All Adults*

**Janet Miller, David Santana and Diana Varela, Public Affair Specialists**

**Location: Salon C**

*This seminar is a unique opportunity to learn in-depth detailed information about the Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) Medicare and Medicaid programs, including eligibility and benefits under each program. The presenters will explain new provisions under the Affordable Care Act including new health insurance options, new Medicaid eligibility group, and other provisions that benefit individuals in need of health care coverage.*

# CONFERENCE SCHEDULE

Friday, June 29, 2012

1:45 p.m. - 3:00 p.m.    **Breakout Sessions: 300 Series continued**

## **302 Shunt Infections**

*Intended Audience: All*

**Jay Riva-Cambrin, MD**

**Location: Brookside A**

*Shunt infections remain the single most common complication of shunting and continue to result in multiple operations and risk for those with hydrocephalus. They can sometimes be hard to diagnose and treatment is not always successful. This talk reviews the source of infection, how they can be recognized and the common ways to treat them. Where do they come from? What do they do? How do we detect them and eliminate them?*

## **303 Neuropsychology and Older Adults (NPH and First Generation Congenital)**

*Intended Audience: NPH and Older Adults*

**Cynthia Smith, Ph.D.**

**Location: Brookside B**

*Neuropsychological evaluation is a critical part of diagnosis for adults with hydrocephalus. This presentation will review neuropsychological findings associated with hydrocephalus in adulthood, including NPH.*

## **304 HA WALKs and Special Events:**

**Are You Ready to Start an HA Fundraising Event in Your Community?**

*Intended Audience: All*

**Randi Corey**

**Location: Salon B**

*HA WALKs and Special Events — all volunteer initiated and coordinated — raised over \$1 million in 2011, more than 50% of HA's total annual revenue. If you've thought of starting a HA WALK (or other event) in your community, this will give you the information you need to decide if starting and Chairing an HA WALK is a good fit for you. Perhaps HA's newest fundraising initiative — School WALKs — might be more up your alley. Learn about the basic requirements of these events (and/or other fundraisers) and how to get started.*

## **305 Headaches and Shunts, and the Medical Management of Headaches**

*Intended Audience: All Ages (not intended for NPH)*

**Harold Rekate, MD and Adrian Goldzsmidt, MD**

**Location: Salon A**

*Headaches are more common when an adolescent or a young adult has a shunt. It is not always due to shunt malfunction and may not be amenable to shunt manipulation. Dr. Rekate will describe how one can find out what the relationship is between headaches and the causes of the hydrocephalus, followed by Dr. Goldzsmidt who will discuss the medical management of headaches when it isn't a shunt malfunction.*

## **306 Measuring Outcome Using the Hydrocephalus Outcome Questionnaire**

*Intended Audience: Parents of Children, Teens and Adults*

**Abhaya Kulkarni, MD**

**Location: Salon F**

*This session will discuss the assessment of quality of life in hydrocephalus, with concentration on the use of the Hydrocephalus Outcome Questionnaire as a research and clinical tool.*

# CONFERENCE SCHEDULE

Friday, June 29, 2012

3:00 p.m. - 3:30 p.m. **Afternoon Break**

**Exhibit Area**

3:30 p.m. - 4:45 p.m. **Breakout Sessions: 400 Series**

## **401 Adolescents and Young Adults with Hydrocephalus: Neuropsychological Issues and Possible Solutions**

*Intended Audience: Parents, Teens and Young Adults*

**Andy Zabel, Ph.D.**

**Location: Salon A**

*Medical advances have expanded the lifespan of individuals with conditions such as obstructive hydrocephalus well into adulthood. While historically considered a medical population, individuals with histories of hydrocephalus are now living longer and are increasingly transitioning into adult health care systems. Neuropsychological consultation and rehabilitation can be an important part of this health care transition, particularly for individuals with cognitive difficulties. This presentation will review neuropsychological findings associated with hydrocephalus in childhood and adolescence, and will provide practical strategies for addressing some of the associated problems commonly experienced in academic, vocational, and social functioning. A specific emphasis will be placed upon the challenges faced by youth with histories of hydrocephalus as they move into the roles and responsibilities of adulthood.*

## **402 If it's not NPH what is it?**

*Intended Audience: NPH*

**Robin Wilson, MD, Ph.D.**

**Location: Salon B**

*NPH can lead to gait impairment, cognitive slowing & reduced bladder control, which are common problems in the elderly population in general. What other disorders cause these problems? How can we tell if the symptoms are caused by something other than NPH? Are there treatments for these symptoms if the cause isn't NPH?*

## **403 How to Start and Lead a Hydrocephalus Support Group in your Area**

*Intended Audience: All*

**Jennifer Bechard and Debby Buffa**

**Location: Salon C**

*If you find yourself with a desire to make a difference in your community and start a local support group in your area, this workshop will give you the tools to get going, including suggestions on locations for support group meetings, how to get the word out, and the best format for your group.*

## **404 SHYMA vs. LOVA — what does this mean?**

*Intended Audience: Adults Diagnosed in Young and Middle-Age (And Their Families)*

**Mark Luciano, MD, Ph.D.**

**Location: Salon F**

*Adult onset congenital hydrocephalus, variously called "SHYMA, LOVA and LISA", is characterized by a hydrocephalus which likely has existed since birth but with symptoms starting in adulthood. Although increasingly recognized, this problem can still be missed or considered as "self-arrested hydrocephalus." This talk discusses the recognition of this type of hydrocephalus and the unique issues in its treatment.*

# CONFERENCE SCHEDULE

**Friday, June 29, 2012**

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5:00 p.m. - 6:00 p.m

**Motivational Keynote Address**

*Grand Ballroom Salons D&E*

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**Captain Mark Kelly**

**Commander of the Space Shuttle Endeavour's Final Mission**

Mark Kelly is an American astronaut, retired US Navy Captain, best selling-author, prostate cancer survivor, and an experienced naval aviator who flew combat missions during the Gulf War. The winner of many awards, including the Legion of Merit, two Defense Superior Service Medals and two Distinguished Flying Crosses, Kelly was selected as an astronaut in 1996. He flew his first of four missions in 2001 aboard Space Shuttle Endeavour, the same space shuttle that he commanded on its final flight in May 2011. He has also commanded Space Shuttle Discovery and is one of only two individuals who have visited the International Space Station on four different occasions.

Already a celebrated American, Kelly became the center of international attention after the January 2011 assassination attempt on his wife, former US Congresswoman Gabrielle Giffords. In their best-selling memoir, *Gabby*, the couple shares their story of hope and resilience with the world. The inspirational memoir has topped multiple best-seller lists, including the New York Times, the Wall Street Journal, USA Today, and Amazon. Kelly and Giffords have captivated the nation with their story, appearing in an exclusive Diane Sawyer interview, and on Nightline and The Daily Show, among others, and have appeared on the covers of People and USA Today. Named one of the Esquire's 2011 "Americans of the Year," Kelly was also featured on the cover of and profiled in the magazine. Kelly is currently working on a children's book titled *Mousetronaut: A Partially True Story*, which is expected to be released in October 2012.

Kelly's identical twin brother, Scott, is also an astronaut who served as commander of both the Space Shuttle and the International Space Station. They share the distinction of being the only siblings who have traveled in space.

With 6,000 flight hours in more than 50 different aircraft, 375 aircraft carrier landings, 39 combat missions and more than 50 days in space, Astronaut Mark Kelly is one of our country's most experienced pilots.

A sought-after keynote speaker, Mark Kelly is an American hero who inspires others to be their best while remaining true to their core values. He exemplifies leadership, the importance of teamwork and courage under pressure.

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7:30 p.m. - 9:30 p.m

**Movie Night!**

*Salon F*

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# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

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7:00 a.m. - 5:00 p.m.	<b>Conference Registration Open</b>	<b>Grand Ballroom Foyer</b>
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7:30 a.m. - 8:30 a.m.	<b>Continental Breakfast</b>	<b>Grand Ballroom Foyer</b>
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8:30 a.m. - 9:45 a.m.	<b>Breakout Sessions: 500 Series</b>
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## **501 Pregnancy and Hydrocephalus**

*Intended Audience: Parents and Young Adults*

**Mark Luciano, MD, Ph.D., and Pedro Arrabal, MD**

**Location: Salon A**

*It is critical for women of child bearing age who are living with hydrocephalus to seek specialized medical advice if they become pregnant. Careful preconception counseling and management by a team of obstetricians, geneticists, neurosurgeons, and neurologists will enable these patients to accomplish a successful pregnancy. This session will address the risks and benefits of various management options for shunt dependent pregnant women, including prenatal testing and delivery of the baby.*

## **502 Cognitive Remediation and Neuropsychology**

*Intended Audience: Parents of school-aged children*

**Lori Day, Ph.D.**

**Location: Salon B**

*The focus of this session will be to introduce the audience to current strategies utilized for intervention. The strengths and weaknesses of these approaches will be reviewed. This review will lead us to the development of a focused remediation program for children born with hydrocephalus.*

## **503 Teens Take Charge**

*Intended Audience: Parents and Teens*

**Jennifer Bechard and TTC Advisory Council**

**Location: Salon C**

*Making the transition from childhood to adulthood can be tricky for anyone but when you are living with a chronic health condition, it is extremely important that you learn how to stand up for yourself and get what you need. Teens Take Charge is an exciting new advocacy program for teens affected by hydrocephalus. Come and learn from this vital group of teenagers and find out how you can get involved.*

## **504 Thinking Your Way Through Difficult Medical Decisions**

*Intended Audience: All*

**Michael Williams, MD, Cynda Rushton, Ph.D., RN, FAAN, Emily Fudge and Russell Fudge**

**Location: Salon F**

*Although it is a topic that can be uncomfortable to contemplate, people with hydrocephalus of 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. By the end of this session, participants will be able to identify two resources for hospice, palliative care, advance care planning and end-of-life decisions for children or adults as appropriate.*

# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

## **505 Spasticity and Gait Disorders in Adults and Children with Hydrocephalus**

*Intended Audience: NPH*

**Scott Brown, MD**

**Location: Brookside AB**

*Spasticity is the stiffness and spasm that occurs after injury or disease to the central nervous system. It can cause pain and affect many functional activities such as walking (gait) and self care. This session will describe the manifestations of spasticity and the interventions available to treat it.*

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10:00 a.m. - 11:15 a.m.

**Breakout Sessions: 600 Series**

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## **601 ABCs of IEPs**

*Intended Audience: Parents of School-Aged Children*

**Andy Zabel, Ph.D.**

**Location: Salon A**

*This presentation will provide session attendees with an overview of the IEP process as it applies to youth with histories of hydrocephalus. An emphasis will be placed upon areas of educational need commonly identified in students with hydrocephalus, as well as school-based intervention/accommodation techniques that can often be effective in addressing these problems. Tools for writing effective IEPs will be discussed and strategies will be given to help parents of students with hydrocephalus interact with IEP-planning teams in an effective manner to get necessary services and accommodations.*

## **602 The Role of Physiatry in the Care of Adults and Children with Hydrocephalus**

*Intended Audience: NPH, Adults*

**Scott Brown, MD**

**Location: Salon B**

*Physiatrists are physicians who specialize in the medical specialty of Physical Medicine and Rehabilitation. This session will describe how Physiatrists look at impairments caused by disease and use a team approach to focus on functional restoration.*

## **603 Slit Ventricle Syndrome**

*Intended Audience: Parents, Teens and Young Adults*

**Harold Rekate, MD**

**Location: Salon C**

*This session will discuss the incidence and management of slit ventricle syndrome in patients shunted early in life. The discussion will include the typical findings on imaging studies as well as the clinical course and options for management. The intended audience for this session is patients and/or parents who were shunted in infancy who have small ventricles.*

# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

## **604 Genetics and Hydrocephalus**

*Intended Audience: All*

**Michael Williams, MD and J. Pat McAllister, Ph.D.**

**Location: Salon F**

*Many patients and families worry about the possibility that hydrocephalus can be inherited or has a genetic basis. This session will review current knowledge regarding the genetics of hydrocephalus, which is rarely caused by a single gene mutation. Rather, a wide variety of genetic variation may increase a person's susceptibility to develop hydrocephalus.*

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11:15 a.m. - 11:45 a.m. **Coffee Break**

**Exhibit Area**

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11:45 a.m. - 12:45 p.m. **Historical Perspective of Hydrocephalus and its Treatment**  
**HA History: 1983 - 2012 - Then, Now and the Future**

**Grand Ballroom Salons D&E**

***Presenters:***

- ◆ James Goodrich, MD
- ◆ Carlos Hakim, Ph.D.
- ◆ Emily Fudge, HA Founder
- ◆ Marion Walker, MD

Dr. Goodrich will explain the treatment of hydrocephalus as it has evolved over the last 2500 years. Up until the 18th century hydrocephalus, as a clinical disorder, was not well understood nor well treated. In the reviewing the history of hydrocephalus one will see how poorly treated this disorder has been treated in the past. Dr. Hakim will be talking about the historical perspective of Normal Pressure Hydrocephalus, its first description by Dr. Salomon Hakim and the original theories behind it. Emily will share some thoughts on the history of the Hydrocephalus Association.

***Presentation of Life Time Achievement Awards***

Dawn Mancuso, Paul Gross, and Marion Walker, MD

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12:45 p.m. - 1:45 p.m. **Luncheon with Inspirational Keynote Address** **Grand Ballroom Salons D&E**  
**Hydrocephalus in Sub-Saharan Africa**

***Presenter:***

- ◆ Benjamin Warf, MD

# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

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2:00 p.m. - 3:15 p.m.     **Breakout Sessions: 700 Series**

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**701 Shunt Building Workshop - Make Your Own Shunt!**

*Intended Audience: All*

Leanne Lintula, Medtronic

**Location: Brookside AB**

*This workshop will include hands-on work with individual valve components including the fabrication of a fixed pressure (nonadjustable) valve. Attendees will have the opportunity to see the size and shape of actual valve parts and will take home their own valve assembly. No latex is involved in the workshop.*

**702 Workplace Communication Tips for People Living with Disabilities**

*Intended Audience: Adults, NPH*

Dave Carl, MSW and Sam Marks

**Location: Salon B**

*Getting a job is not easy - it can be overwhelming for anyone. It doesn't matter whether you are a person with a disability or not. One of the most important skills needed in any workplace is simple communication. As individuals with spina bifida and hydrocephalus, Sam Marks and Dave Carl will share their professional and personal experiences in the workplace. They will also give tips on how to gain confidence to overcome obstacles and learn skills needed to communicate in the workplace.*

**703 Clinical Trials**

*Intended Audience: All*

Michael Williams, MD

**Location: Salon C**

*Clinical research trials are necessary to determine if new treatments are effective or new tests are accurate. This session will discuss what it means to participate in a clinical trial and will identify important questions to ask before you decide whether to participate.*

**704 Special Needs of Parenting**

*Intended Audience: Parents of Young Children*

Stephen Trudeau, Ph.D.

**Location: Salon F**

*The Special Needs of Parenting aims to help parents and caregivers more fully understand what they are going through in terms of the unique challenges of parenting a special needs child. Exploring the concepts of processing the loss of the ideal child and "chronic sorrow" issues will help the parents to be more effective. We will also discuss parenting styles, managing friendships and taking care of yourself.*

# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

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3:15 p.m. - 3:45 p.m. **Afternoon Break**

**Exhibit Area**

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3:45 p.m. - 5:00 p.m. **Breakout Sessions: 800 Series**

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**801 NPH- When the Shunt No Longer Works**

*Intended Audience: NPH*

**Robin Wilson, MD, Ph.D.**

**Location: Salon B**

*Attendees will learn what happens if NPH symptoms return, including diagnostic evaluation and management options.*

**802 Special Need Trusts and Estate Planning**

*Intended Audience: All*

**Larry Rivkin**

**Location: Salon C**

*As family members of a person with a disability, we so often tend to view life in light of the challenges presented to us. Topics of discussion include: how to create a map of the future, how to prepare legally and financially, how to incorporate and maximize government benefits, how to prepare for transition and how to communicate your Special Needs Trust and Estate Planning to your family.*

**803 Laughing at the Elephant**

*Intended Audience: All*

**Tom Smith & Sam Marks**

**Location: Salon A**

*People living with hydrocephalus often feel like the "others" in social settings. Humor is a great social lubricant and learning how to break the ice with it can level the most difficult playing field. Tom Smith and Sam Marks will discuss finding the humor in life from a professional and personal standpoint. Participants will learn how to use humor in interactions with others to make friends and break barriers. Using improv and stand-up techniques, Smith and Marks will talk about how, what, why, and when humor works—all in a fun environment where failure and success are not the measure.*

# CONFERENCE SCHEDULE

**Saturday, June 30, 2012**

6:00 p.m. - 9:30 p.m. **Dinner Dance & Talent Show**

*Grand Ballroom Salons D&E*



**Sunday, July 1, 2012**

8:00 a.m. - 11:00 a.m. **Conference Registration Open**

*Grand Ballroom Foyer*

8:00 a.m. - 9:00 a.m. **Continental Breakfast**

*ABC Foyer*

9:00 a.m. - 10:30 a.m. **Intergenerational Panel of Experts**

*Salon ABC*

**Presenters:**

- ◆ Michael Williams, MD and Panel

People living with Hydrocephalus, and their loved ones, will speak openly and candidly about how hydrocephalus affects them. Dr. Michael Williams will be moderating the panel.

10:30 a.m. - 11:00 a.m. **Farewell and Closing Remarks**

*Salon ABC*

- ◆ Dawn Mancuso, MAM, CAE, FASAE, CEO, Hydrocephalus Association
- ◆ Marion Walker, MD
- ◆ Michael Williams, MD

## TEENS TAKE CHARGE



**Change** often begins with the teenager. Teens have energy, they have enthusiasm and they definitely have creativity. Making the transition from childhood to adulthood can be tricky for anyone, but when you are living with a chronic health condition such as hydrocephalus, it is extremely important that you learn to stand up for yourself, and get what you need. The Hydrocephalus Association's new teen program - Teens Take Charge (TTC) trains teenagers and young adults (and their siblings), who are affected by hydrocephalus, to become self-advocates with both health professionals and with their legislators. The program provides support, trainings and awareness and fundraising opportunities so that teens can be an effective force in making their stories heard with their representatives. The Medtronic Foundation has made it possible for HA to create a real "teen community" that is making great strides around the primary goals of the program.

The Teens Take Charge Advisory Council is made up of nine articulate, creative, enthusiastic teenagers who are ready and willing to take a stand against hydrocephalus! Follow them as they post updates, talk about the Advisory Council and Teens Take Charge Program. Please meet the Advisory Council: Ashley Snyder, Nicole Padron, Elijah Lawrence, Megan Rivkin, Chiara Rocciola, Wyatt Barris, Madison Pardi, Lexi Rocciola and Harrison Silver.

**Join the program online:** [www.hydroassoc.org](http://www.hydroassoc.org)

**Facebook:** <http://www.facebook.com/TeensTC>

**Twitter:** <http://twitter.com/%21TeensTC>

Email: [Jenn@hydroassoc.org](mailto:Jenn@hydroassoc.org)

**JOIN US AND HELP CREATE A COMMUNITY OF TEENS MAKING CHANGES HAPPEN!**

# CONFERENCE FACULTY BIOGRAPHIES

**Michael Altman, MD**

Krieger Eye Institute At Sinai  
Baltimore, MD

Dr. Michael Altman grew up in a small town in the suburbs of New York City. He proceeded to graduate Medical school from The Albert Einstein College of Medicine in the Bronx NY and was accepted to his Ophthalmology Residency which he completed with distinction at The Krieger Eye Institute at Sinai Hospital in Baltimore Maryland. After residency he then sought further expertise, with higher level specialty training, in two of the more challenging realms within Ophthalmology achieving two separate Fellowships; one in Pediatric Ophthalmology and the second in Neuro Ophthalmology. Dr Altman is currently the director of Pediatric Ophthalmology as well as Neuro ophthalmology at Sinai Hospital of Baltimore where he combines these two specialties in an effort to serve patients with unique visual system disease states and to care for children with all types of neurologic disorders that affect the eyes.

**Pedro Arrabal, MD**

The Louis and Henrietta Blaustein Women's Health Center  
Maternal-Fetal Medicine, Sinai Hospital of Baltimore  
Baltimore, MD

Pedro P. Arrabal, M.D., serves as the Medical Director for the Division of Maternal-Fetal Medicine at Sinai Hospital of Baltimore. He is a board-certified specialist in obstetrics-gynecology and a sub-specialist in Maternal Fetal Medicine. His special interests include prenatal diagnosis and management of fetal anomalies, the evaluation of fetal well-being, and the evaluation and management of medical disorders of pregnancy such as diabetes, hypertension, cardiac, autoimmune, and renal disorders.

**Jennifer Bechard,**

Support Liaison, Hydrocephalus Association  
Northville, MI

Whether she is lying in a hospital bed or crossing a finish line, 24-year-old Jennifer Bechard doesn't let hydrocephalus stop her from acting on her passion: leading the HA Teens Take Charge Program, supporting the Hydrocephalus Association's series of fundraising walks. Jenn has led three Hydrocephalus Walks in her native Michigan, leads a support group and voluntarily designs walk websites for chapters across the country, often from her hospital bed. (Over the years, Jenn, a Northville, MI resident, has undergone more than 90 brain surgeries.)

**Scott Brown, MD**

Physical Medicine & Rehabilitation, Sinai Hospital  
Baltimore, MD

Scott E. Brown, MD is chairman of the departments of Physical Medicine and Rehabilitation across the LifeBridge Health System in Baltimore, Maryland, including Sinai Hospital of Baltimore, Northwest Hospital Center, and Levindale Hebrew Geriatric Center and Hospital. He is board certified in Physical Medicine and Rehabilitation and Pain Medicine as well as electrodiagnostic medicine. Dr. Brown is co-director of neurophysiology at the Sandra and Malcolm Berman Brain and Spine Institute at LifeBridge. His special interests include treatment of spasticity and gait disorders, pain management, electrodiagnostic testing for neuromuscular disorders, and treating the medical problems of musicians and dancers. He is the biographer of the jazz pianist/composer James P. Johnson..

**Debby Buffa**

HA Board Member  
St. Louis, MO

Debby Buffa is a mother of two daughters with hydrocephalus who are now adults. In the 1980's she founded a support group in St. Louis, MO that has been integrated into the Hydrocephalus Association. She has been a member of the HA Board of Directors since 2005 and is the manager of a neurosurgical practice in St. Louis.

**Dave Carl, MSW**

Richland, WA

Dave Carl is a social worker from Washington State. Living with spina bifida and hydrocephalus he uses his life experiences to help others with disabilities gain skills necessary for future employment. Dave is also a motivational speaker, writer and blogger teaching people with and without disabilities of all ages how to overcome obstacles in life.

**Randi Corey**

Director of Special Events, Hydrocephalus Association  
Raleigh, NC

Randi has worked in the non-profit health arena for over 20 years. She served as the State Director of the NC Chapter of the March of Dimes for almost six years, and as the Executive Director of the Eastern NC Chapter of the Juvenile Diabetes Research Foundation for eight years after transferring to North Carolina from the upstate NY area. While in upstate NY Randi was the Executive Director of the NENY Chapter of the Cystic Fibrosis Foundation. Randi has worked with volunteers throughout her career and is a walk-a-thon expert, having personally coordinated 11 events raising almost \$5 million and supervising 147 walks raising \$11 million. Randi has worked with dozens of volunteer Board and committees throughout her career and loves the passion and energy volunteers bring to an organization. She joined the Hydrocephalus Association as a consultant in March 2010.

**Jan Crye, OTR/L, CDRS**

Sinai Rehabilitation Center, Sinai Hospital  
Baltimore, MD

Jan Crye is a 1978 graduate of Elizabethtown College, Elizabethtown, PA with a BS in occupational therapy. She has a background of working in various settings including psychiatry, home health and physical rehabilitation. In 1993 she joined the staff of Siskin Hospital for Physical Rehabilitation in Chattanooga, TN to assume responsibility for the vision and driving rehabilitation programs. In 2008, she relocated to Baltimore to assume the driving rehabilitation program at Sinai Hospital. She is certified through the Association of Driver Rehabilitation Specialists and has performed over 7000 driving assessments with patients of varied diagnoses in her career.

**Russell and Emily Fudge**

Hydrocephalus Association Founders  
San Francisco, CA

Russell and Emily Fudge, of San Francisco, are two of the founders of the Hydrocephalus Association. Emily served as the Executive Director for 20+ years and Russell continues as a member of the Board of Directors, a position he's held since the founding. Their son Gerard was diagnosed with hydrocephalus in 1981 at the age of 11. He died in 1992. The first Hydrocephalus Association Scholarship was established in 1994 by the Fudge Family and their friends, in memory of Gerard.

# CONFERENCE FACULTY BIOGRAPHIES

**Adrian J. Goldszmidt, MD**

LifeBridge Health Brain & Spine Institute  
Baltimore, MD

Adrian J. Goldszmidt, M.D., is chief of the Department of Neurology at Sinai Hospital. Dr. Goldszmidt also heads the Stroke Center and Headache Program for the LifeBridge Health Brain & Spine Institute. Dr. Goldszmidt received his medical degree from the Harvard Medical School. He completed an internship in internal medicine at Massachusetts General Hospital and a residency in neurology at the Longwood Neurology Training Program (Harvard University) in Boston. Following his residency, Dr. Goldszmidt was a fellow at the New England Medical Center and Spaulding Rehabilitation Hospital, where he pursued his interest in learning more about stroke. He is co-author of "Stroke Essentials," a guide for neurologists. Board certified in neurology, Dr. Goldszmidt's clinical interests include stroke and headache.

**James Goodrich, M.D, Ph.D. D.Sci (Hon)**

Children's Hospital at Montefiore  
Bronx, NY

Dr. Goodrich did his undergraduate work at the University of California, Irvine and completed his graduate work at the Graduate School of Arts and Sciences of Columbia University receiving a Masters and Doctorate of Philosophy. He received his Doctorate of Medicine from Columbia University College of Physicians and Surgeons. Intern and residency training was completed at the Presbyterian Hospital in the City of New York and the New York Neurological Institute. Dr. Goodrich presently is director of the Division of Pediatric Neurosurgery at the Children's Hospital at Montefiore and holds the academic rank of Professor of Clinical Neurological Surgery, Pediatrics, Plastic and Reconstructive Surgery at the Albert Einstein College of Medicine. The Children's Hospital at Montefiore was recently ranked by US News and World Report as the number #1 children's hospital in the USA for patient satisfaction. Dr. Goodrich holds the Rank of Professor Contralto of Neurological Surgery at the University of Palermo in Palermo, Italy. Dr. Goodrich was recently awarded a Doctorate of Science (Honoris Causa) by the College of Mount St. Vincent, Riverdale, New York. Dr. Goodrich and the team at the Children's Hospital of Montefiore received the "Mayor's Award in Science and Technology" given at City Hall, New York City by Mayor Bloomberg for the successful surgical separation of the Aguirre craniopagus twins.

**David Gordon, MD**

LifeBridge Health Brain & Spine Institute  
Baltimore, MD

David A. Gordon, M.D., FACS, specializes in Neuro-Urology and Voiding Dysfunction. He is currently is Director of the Division of Pelvic NeuroScience at the LifeBridge Center for Urologic Specialties and Chief of Urology at the Leivindale Chronic Hospital and Neuro-Rehabilitation Center. Dr. Gordon received his MD from the Medical Collage of Pennsylvania in Philadelphia. After finishing his urology residency, he went on to pursue a post-doctoral NIH-funded research fellowship in uropharmacology and neuro-urology, also at the University of Pennsylvania. Subsequently, he was involved in muscarinic receptor profiling, as well as many phases of the FDA approval process for agents and interventions used to treat bladder dysfunction. At this time, he continues to utilize his basic science skills to oversee one of the research laboratories at The Sinai Hospital of Baltimore where he is conducting projects that deal with "stem cell migration" in the bladder. Dr. Gordon is a member of many professional societies, including the American Urologic Association, the International

Continence Society, the Bladder Research Council, and Pelvic Health Education Initiative. Currently, he runs the Neuro-Urology Fellowship program at LifeBridge and is Assistant Clinical Professor of Urology at the University of Maryland. Finally, he has co-authored a number of paperbacks, book chapters and journal articles, as well as lectured widely on various topics in urology, including neurogenic bladder, urinary incontinence, and pelvic nerve conduction problems.

**Paul Gross**

HA Board Chair  
Woodinville, WA

Paul Gross is between commercial jobs at this time and focusing his efforts on various not for profit efforts since winding down his web startup – Sampa. Prior to becoming the CEO of Sampa, Mr. Gross was a Senior Vice President with the Microsoft Corporation and with Borland International. In addition to his work as a software executive, he is a very active venture philanthropist who has worked in education and medical research. He is Chairman of the Hydrocephalus Association, the co-founder of the Hydrocephalus Clinical Research Network ([www.hcrn.org](http://www.hcrn.org)), the founder of MX for Children ([www.mxforchildren.org](http://www.mxforchildren.org)), and the founder of PH144 Ventures LLC which is doing research and development of novel shunt technology, and a partner in Social Venture Partners. In his personal life, he is married to Lori Poliski, is the father of two children – one of whom has hydrocephalus, and is an avid Ultimate Frisbee player and mountain biker.

**Carlos Hakim, Ph.D.**

Neuroscience Laboratory  
Fundacion Santa Fe

Bogota, Colombia  
Carlos Hakim, Ph.D., trained in a combined MIT - Harvard Medical School program. His father, Salomon Hakim, a neurosurgeon who was the first to identify Normal Pressure Hydrocephalus (NPH), developed one of the most used valves based upon a ball-in-cone design. Carlos innovated his father's design and invented the programmable valve which he developed and manufactured in Switzerland using craftsmen from the watch making industry. This valve can be adjusted to any of 18 different pressures settings by using an external programmer that is held on the scalp over the implanted valve, allowing surgeons to match the pressure to the patient's needs without performing an operation to adjust the valve's pressure. This concept was introduced by both Salomon and Carlos at the first patient conference organized by the Hydrocephalus Association. Dr. Carlos Hakim is co-founder and Director of the Neuroscience Laboratory at the Fundacion Santa Fe in Bogota, Colombia. His research interest is in the study of the hydrodynamics of the cranial cavity and the pathophysiology of NPH, where the combination of medicine and engineering complement themselves.

**John R. W. Kestle, MD**

University of Utah and Primary Children's Medical Center  
Park City, Utah

John Kestle was born in Toronto and educated at the University of Western Ontario (BSc Biology 1980; MD 1984) and at McMaster University (MSc, Epidemiology and Biostatistics 1989). He did a surgical internship at St. Michael's Hospital in Toronto (1984-1985) before training in neurosurgery at the University of Toronto. At the end of neurosurgical training, he completed a six month fellowship in peripheral nerve surgery with Drs. Alan Hudson and Susan McKinnon and a one year fellowship in pediatric neurosurgery at

# CONFERENCE FACULTY BIOGRAPHIES

the Hospital for Sick Children in Toronto. Dr. Kestle joined the faculty of the University of British Columbia in 1992 and was on the Surgical staff at British Columbia's Children's Hospital in Vancouver for six years. In 1998, he joined the faculty at the University of Utah and Primary Children's Medical Center. He is currently Professor of Neurosurgery, Director of the Residency Training Program and Chief of the Division of Pediatric Neurosurgery. His clinical practice has been exclusively in pediatric neurosurgery with a specific interest in pediatric epilepsy surgery. His research is in clinical trials methodology and he has developed a multi-center network for running clinical trials in pediatric neurosurgery. He is Chair of the Hydrocephalus Clinical Research Network, a network for clinical research in hydrocephalus with 5 participating centers and a data center in Salt Lake City. He has published 111 articles and chapters. He mentors neurosurgical residents in the MPH program in clinical research methods, epidemiology and biostatistics.

## **Abhaya Kulkarni, MD, MSc, PhD, FRCSC**

The Hospital for Sick Children, University of Toronto  
Toronto, Canada

Dr. Kulkarni obtained his MD degree in 1994 and his Neurosurgery certification in 2002. Following this he completed fellowship training in pediatric neurosurgery at Hôpital-Necker Enfants Malades in Paris. He joined the Hospital for Sick Children in the Division of Neurosurgery in 2003. His clinical interests span the spectrum of pediatric neurosurgery, including hydrocephalus, neuro-oncology, head injury and craniofacial surgery. He is also actively involved in stereotactic radiosurgery at the Toronto Gamma Knife Unit. Since 2010, he has served as the Neurosurgery Residency Program Director at the University of Toronto. Dr. Kulkarni's research interest is in the area of clinical epidemiology, specifically the study of long-term health outcomes in pediatric neurosurgical patients. He completed his PhD in 2003 in the Department of Clinical Epidemiology and Biostatistics at McMaster University. His PhD thesis led to the development of the first health status outcome measure for use in pediatric hydrocephalus. He is a lead site investigator for the North American Hydrocephalus Clinical Research Network and serves as an Associate Editor for Neurosurgery.

## **Story Landis, Ph.D.**

National Institute for Neurological Disorders and Stroke  
Bethesda, MD

Story Landis, Ph.D. has been Director of the National Institute for Neurological Disorders and Stroke (NINDS) since 2003. A native of New England, Dr. Landis received her undergraduate degree from Wellesley College (1967) and her Ph.D. from Harvard University (1973). After postdoctoral work at Harvard University, she served on the faculty of the Department of Neurobiology there. In 1985, she joined the faculty of Case Western Reserve University School of Medicine, where she created the Department of Neurosciences which, under her leadership, achieved an international reputation for excellence. Throughout her research career, Dr. Landis has made fundamental contributions to the understanding of nervous system development. She has garnered many honors, is an elected fellow of the Institute of Medicine, the Academy of Arts and Sciences, the American Association for the Advancement of Science and the American Neurological Association, and in 2002 was elected President of the Society for Neuroscience. Dr. Landis joined the NINDS in 1995 as Scientific Director and worked to re-engineer the Institute's intramural research programs. Between 1999 and 2000, she led the movement, together with the NIMH Scientific Director, to bring a sense of unity and common purpose to 200 neuroscience

laboratories from eleven different NIH Institutes. As NINDS Director, Dr. Landis oversees an annual budget of \$1.5 billion that supports research by investigators in public and private institutions across the country, as well as by scientists working in its intramural program. Together with NIMH and NIA directors, she co-chairs the NIH Blueprint for Neuroscience Research, a roadmap-like effort to support trans-NIH activities in the brain sciences. In 2007, Dr. Landis was named Chair of the NIH Stem Cell Task Force.

## **John A. Lawrence**

Chief of Staff

Democratic Leader, U.S. House of Representatives  
Washington, DC

John A. Lawrence is the Chief of Staff to the Democratic Leader of the U.S. House of Representatives, Congresswoman Nancy Pelosi (D-CA-8), a position he also held 2005-2006. He served as Chief of Staff during her four years as Speaker of the House of Representatives (2007-2010). He has worked in high-level positions in the House since 1975, including as Democratic Staff Director of the Committee on Education and the Workforce, Staff Director of the Committee on Natural Resources, and Chief of Staff and Legislative Director to Congressman George Miller (D-CA-7). Among his areas of legislative policy expertise are children and family, education, natural resources and energy, and labor. Mr. Lawrence was born in Paterson, N.J., and holds a Ph.D. in American History from the University of California (Berkeley), and an A.B. from Oberlin College

## **Mark Luciano, MD, Ph.D., FACS**

Cleveland Clinic

Cleveland, OH

Mark G. Luciano, MD, PhD, FACS, came to the Cleveland Clinic Department of Neurosurgery in 1993 after training in general neurosurgery at the University of Pennsylvania and in pediatric neurosurgery at Harvard's Boston Children's Hospital. In addition, he was trained in research through a PhD from Tulane University and a fellowship at the National Institutes of Health. At Cleveland Clinic, he also holds adjunct positions in neuroscience research and in biomedical engineering. Dr. Luciano is board-certified in general neurosurgery and in pediatric neurosurgery. He is Head of Congenital and Pediatric Neurosurgery and Co-Director of the Pediatric Neurology Center at Cleveland Clinic. His patients are children and adults with neurological congenital anomalies, hydrocephalus, cerebral cysts, tumors, craniofacial anomalies, tethered cord, Chiari malformation and cerebral palsy. As part of his section, Dr. Luciano also directs the Neuroendoscopy and CSF Disorders program. He is known nationally and internationally for his clinical activity, research and educational work in neuroendoscopy, a form of minimally invasive neurosurgery. Children and adults are referred who are in need of endoscopic procedures, such as those with ventricular tumors and cysts. Dr. Luciano has directed Cleveland-area, national and international courses in neuroendoscopy and has developed new techniques in minimally invasive neurosurgery. Dr. Luciano is recognized as an international leader in hydrocephalus. His NIH-funded experimental research has centered on the brain's adaptation to the chronic compression and hypoxia of hydrocephalus and on the dynamic relationship between the CSF and vascular systems. Dr. Luciano is an Adjunct Faculty member for Kent State and Cleveland State Universities and is training PhD graduate students in both engineering and neuroscience. His experimental work also has led to his invention and development of a novel device to increase cerebral blood flow. At Cleveland Clinic, Dr. Luciano initiated the first multidisciplinary clinic in the country to

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diagnose and treat NPH, an increasingly recognized reversible form of imbalance and dementia. The "Aging Brain Clinic" or NPH Screening Clinic (Normal Pressure Hydrocephalus Screening Clinic) triages elderly patients with problems in balance and cognition. This clinic is a national role model for NPH diagnosis and treatment. As a result of his recognized leadership in hydrocephalus, Dr. Luciano has been on the National Hydrocephalus Association advisory board and has appeared in the local and national press and television including the Wall Street Journal, Good Morning America, and the Today Show. In addition to national publications, peer-review and editorial activity, Dr. Luciano is an internationally invited speaker in neuroendoscopy, hydrocephalus and pediatric neurosurgery. He was the "Brahm Prakash Memorial Orator" in New Delhi, India, and has been invited as visiting professor and speaker in India, China, Egypt and Europe. He has initiated an international cooperation between Cleveland Clinic and Peking Union Medical Center in Beijing, China, for education in neuroendoscopy. In addition, he has served as host and thesis mentor for international MD research fellows from Egypt and Sweden.

## **Dawn M. Mancuso, MAM, CAE, FASAE**

Dawn Mancuso is the CEO of the Hydrocephalus Association, having joined the organization on December 1, 2011. After initially working in the communications field, Dawn has been a non-profit manager for over 30 years. Prior to working for HA, she served for 15 years as the Executive Director/CEO of the Association of Air Medical Services and its supporting foundation, the MedEvac Foundation International. She has an undergraduate degree in International Relations from Georgetown University and a Master's Degree in Association Management from George Washington University. She is a frequent presenter at association management conferences, and has been published in magazines such as *Association*, *Executive Update*, and other non-profit management publications. She is a past board member of the American Society of Association Executives (ASAE), and is the author of one of the chapters of *Professional Practices in Association Management*, the closest thing to a textbook for those in the association management profession. She also worked with Jim Collins (author of *Good to Great*) as part of the research team and one of the research authors of the book, *7 Measures of Success: What Remarkable Associations Do that Others Don't*, published in 2006. Dawn earned the CAE (Certified Association Executive) designation from ASAE in 1991, and was named a Fellow of ASAE in March of 2001.

## **Sam Marks**

Oakland, CA

Sam Marks is a paralegal working in San Francisco, CA. He received a Bachelor's degree from UC Santa Barbara in 2007. He is a lifelong Bay Area resident, and is active in the Bay Area Outreach and Recreation Program, a sports organization for people with disabilities.

## **James P. "Pat" McAllister, II, Ph.D**

University of Utah  
Salt Lake City, UT

As Professor and Director of Basic Hydrocephalus Research, with joint appointments in Bioengineering and Physiology, Dr. Pat McAllister helps to "glue" a variety of basic research initiatives together with clinical applications. Dr. McAllister received his Ph.D. from Purdue University in 1976, and has held staff positions at the

UCLA Mental Retardation Research Center, Temple University School of Medicine, the Cleveland Clinic Foundation, and the Detroit Medical Center/Wayne State University prior to joining the University of Utah in 2007. Dr. McAllister has dedicated nearly 28 years to the study of hydrocephalus, and recently was given the Robert H. Pudenz Prize for Excellence in Cerebrospinal Fluid Physiology and Hydrocephalus by the International Society for Pediatric Neurosurgery. In addition to advancing our understanding of the neuronal damage that occurs in the hydrocephalic brain and how to reverse it, he is also developing shunt systems that resist cellular obstruction. Dr. McAllister is a recent recipient of the Hydrocephalus Association's Established Investigator grant to study "Novel Neurobiological Interventions for the Treatment of Hydrocephalus".

## **J. Gordon McComb, MD**

Children's Hospital of Los Angeles  
Los Angeles, CA

Dr. McComb began his education by receiving a degree in chemical engineering prior to pursuing a career in neurosurgery. Dr. McComb served our country for two years in the US Air Force as a surgeon in Vietnam before returning to the states to continue his medical education. He joined the medical staff of Children's Hospital Los Angeles in the mid-1970s and for the past 36 years has served as Chief of Neurosurgery. Dr. McComb has published hundreds of clinical and basic research papers, book chapters and abstracts that have advanced the diagnosis and treatment of infants and children with neurosurgical disorders. He has participated in many activities of various neurosurgical organizations and is past president of the American Society of Pediatric Neurosurgery and the Southern California Neurological Society. He is also a member of the board of directors of the National Hydrocephalus Foundation and the Rudi Schulte Research Institute. He has been a member of the editorial board and pediatric section editor of *Neurosurgery* for two decades. His is also pediatric co-section editor of the *World Neurosurgery*, senior advisory board of *Pediatric Neurosurgery* and editorial board of *Journal of Neuro-Oncology*. He is also a founding member of the American Board of Pediatric Neurosurgery. Dr. McComb is a member of the Hydrocephalus Association Medical Advisory Board.

## **Jill Morris, Ph.D.**

Program Director, National Institute for  
Neurological Disorders and Stroke  
Bethesda, MD

I am currently a Program Director at NINDS. My grant portfolio consists of multiple neurological disorders including tuberous sclerosis, neurofibromatosis, hydrocephalus and cerebellar malformations. Prior to coming to the NIH in May of 2011, I was an Assistant Professor in the Department of Pediatrics in the Feinberg School of Medicine at Northwestern University and Children's Memorial Research Center. My laboratory investigated the molecular basis of psychiatric disorders. In particular, I studied the function of DISC1, a schizophrenia susceptibility gene, since its discovery in 2000. I have published multiple papers on DISC1: cloning and expression of the mouse Disc1 gene; identifying DISC1 interactors and protein localization; determining DISC1 expression pattern in the primate brain; characterizing the expression pattern of Disc1 mRNA in the mouse brain throughout development; immunohistochemical analysis of Disc1 expression in the hippocampus; functional studies examining the role of Disc1 in regulating the migration and cell fate of cranial neural crest cells using the zebrafish model system; and functional studies into the

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role of Disc1 in granule cell migration in the developing hippocampus. Briefly, prior to my position at Northwestern University, I was a Senior Research Biologist in the Department of Neuroscience at Merck Research Laboratories. My research at Merck was focused on molecular neuroscience. I directed molecular and cell biology research projects relating to bipolar affective disorder, schizophrenia, Alzheimer's disease and Parkinson's disease. Prior to Merck, I was a Senior Staff Fellow in the Unit of Molecular Neurogenetics in the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH). In addition, I have four years of postdoctoral experience that include positions in the Howard Hughes Medical Institute at the University of Michigan and the NIH. At the NIH, my research successfully led to the identification and the characterization of the gene responsible for the autosomal recessive neurodegenerative disorder called Niemann-Pick type C (NPC) disease.

## **Joseph Piatt, MD, FAAP**

A I DuPont Hospital for Children  
Wilmington, DE

Dr. Piatt is a Professor of Neurological Surgery and Pediatrics at Thomas Jefferson University in Philadelphia, and he practices at the A I duPont Hospital for Children in Wilmington, Delaware. The management of hydrocephalus accounts for a large fraction of his work. He is a member of the Medical Advisory Board of the Hydrocephalus Association and Past-Chair of the Section on Neurological Surgery of the American Academy of Pediatrics

## **Dorothy Poppe**

Executive Director of the Chiari &  
Syringomyelia Foundation (CSF)  
Staten Island, NY

Dorothy lives in Staten Island, New York and has three children – John is an attorney at Legal Aid Society, Mary is a junior at St. Johns University, majoring in Sports Management, and George is a Research Fellow in physics for the CUNY system and will be returning to graduate school. George was also diagnosed with a Chiari malformation and syringomyelia in 1991 and had two surgeries in 1992. Dorothy received a Bachelor's Degree from New York University and a diploma from the Juilliard School in New York City. Dorothy has 17 years of experience in the non-profit arena. She was formerly National Director of Development at the American Syringomyelia Alliance Project for seven years. Prior to that, she worked for four years as a volunteer fundraiser and subsequently served for six years as an ASAP board member. She was instrumental in many projects including the Pediatric Directory and Resource Guide, the Genetic Study initiated by Dr. Thomas Milhorat and Duke University Medical Center, and the formation of a world renowned Medical Advisory Board. She is excited at the prospect of working with CSF's professional board and taking the organization from its grassroots initiative to a national education, research and advocacy group which patients, scientists and medical professionals can rely on. "I am proud to be part of an organization that attracted the caliber of professional colleagues who have joined CSF and believe in our mission."

## **Harold L. Rekate, MD, FACS, FAAP**

Director, Chiari Institute  
Director, Hypothalamic Hamartoma Center  
Professor of Neurosurgery, Hofstra Northshore  
LIJ School of Medicine  
Great Neck, NY

Dr. Rekate served as chairman of pediatric neurosciences and chief of pediatric neurosurgery for more than 25 years at the Barrow Neurological Institute (BNI). While at BNI, Dr. Rekate was a clinical professor of neurosurgery at the University of Arizona College of Medicine. Dr. Rekate completed his undergraduate studies at Duke University and received his medical degree at the Medical College of Virginia. He trained in neurosurgery and pediatric neurosurgery at the University Hospitals of Cleveland and completed his residency training at Case Western Reserve University. Dr. Rekate is board certified by the American Board of Neurological Surgery and the American Board of Pediatric Neurological Surgery. A widely published author of more than 200 publications, most of which are related to cerebrospinal fluid difficulties, including Chiari malformations, syringomyelia and hydrocephalus, Dr. Rekate also served as editor for a number of prestigious medical journals and was chairman of the editorial board of the Journal of Neurosurgery Pediatrics. Over the course of his career, Dr. Rekate has done extensive research regarding spinal fluid flow, receiving funding from the National Institutes of Health and the National Aeronautics and Space Administration. He also has held many local, national and international positions, including chairman of the Joint Section on Pediatric Neurological Surgery of the American Association of Neurological Surgery and the Congress of Neurological Surgery, and president of the American Society of Pediatric Neurological Surgeons and the International Society of Pediatric Neurosurgery. Dr. Rekate has received numerous awards and honors, including the prestigious Pudenz Award of Excellence in Research in Cerebrospinal Fluid Physiology.

## **Jay Riva-Cambrin, MD**

University of Utah and Primary Children's Medical Center  
Park City, Utah

Dr. Riva-Cambrin began his medical studies at the University of Alberta, Canada. After graduating from medical school in June 1998, he completed his residency at the University of Toronto, Canada. He obtained a Masters of Science in Clinical Epidemiology from the University of Toronto under the direction of Dr. James Drake. Dr. Riva-Cambrin completed a postgraduate fellowship in pediatric neurosurgery at The Hospital for Sick Children, University of Toronto in Pediatric Neurosurgery. Dr. Riva-Cambrin's clinical interests in Pediatric Neurosurgery include the treatment of hydrocephalus and clinical trials. He is a member of The Hydrocephalus Clinical Research Network (HCRN). He developed a model which predicts hydrocephalus in pediatric tumor patients. Dr. Riva-Cambrin performs over 250 neurosurgeries per year with 100 surgeries being hydrocephalus surgeries. Dr. Riva-Cambrin joined the faculty of the University of Utah and the Primary Children's Medical Center in 2006 and is an Assistant Professor in the Department of Neurosurgery as well as the Program Director for the Pediatric Neurosurgery Fellowship Program. Dr. Riva-Cambrin is one of the Hydrocephalus Association MYIs' research grant recipients.

## **Larry Rivkin**

Lincolnshire, IL

Larry Rivkin received his undergraduate degree (B.A. with Distinction, Phi Beta Kappa) from Stanford University and his law degree from the University of Chicago Law School, where he was the Lord Bissell Public Service Merit Scholar. He also attained his CERTIFIED FINANCIAL PLANNER™ certification. In 1999, Larry and his wife, Michele, founded the law practice Rivkin & Rivkin, LLC, which concentrates in estate planning, estate and trust

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administration, planned charitable giving, and planning for children with special needs. Larry has taught estate planning as an adjunct professor of the College of Financial Planning and is a member of the Trust & Estates Section of the Illinois Bar Association and the Professional Advisory Committee to the Jewish Federation of Metropolitan Chicago's Legacy and Endowments Committee. He is active with the Y-Adventure Guides program, coaches youth recreational sports, and serves as Vice-President of the Lincolnshire-Prairie View District 103 Board of Education and on the Board of Directors of the Camp Nebagamon Scholarship Fund. Larry and Michele have three children, Megan, Joey, and Brady (who has hydrocephalus), and live in Lincolnshire, Illinois.

## **Amy Rosenbaum**

Washington, DC

Amy Rosenbaum is legislative policy expert with strong ties to Capitol Hill and the Administration and a deep policy, legislative and political background. In 2010, Amy left the Hill after fifteen years, having served for nearly five years as Policy Director for then-Speaker of the House Nancy Pelosi (D-CA). As Policy Director, Amy worked closely with Democratic Leadership in the House and Senate, individual Members, as well as key leadership, committee, and Administration staff to execute the Speaker's Innovation and Science Agenda, the First 100 Hours Plan, the Energy Independence and Security Act, the American Recovery and Reinvestment Act, the American Clean Energy and Security Act, and the America's Affordable Health Choices Act. Prior to working for the Pelosi, Amy served as a senior policy aide on the Committee on Education and the Workforce, policy director for Representative Marty Meehan (D-MA), and a research analyst for Rep. Rosa DeLauro (D-CT) and the Democratic National Committee (DNC). Amy holds a Bachelor of Arts from Cornell University and a PhD from Johns Hopkins University.

## **David Santana Health Insurance Specialist**

Office of External Affairs

Division of National Medicare Training Program

Centers for Medicare & Medicaid Services

Bethesda, MD

David Santana is a Health Insurance Specialist in the Centers for Medicare & Medicaid Services (CMS). David works in the Office of External Affairs in the Division of National Medicare Training Program and is the lead trainer. He is responsible for effectively communicating information about CMS programs and resources available to beneficiaries, caregivers and advocacy groups. David's responsibilities also include the following: conducting Medicare training and education throughout the nation; playing a key role in the development of materials used for the national Medicare training program for CMS contractors and partners; and providing technical assistance to federal, state, and local agencies and organizations about the Medicare program.

## **Judy Schneider**

Washington, DC

Judy Schneider is a specialist on Congress at the Congressional Research Service (CRS), a department of the Library of Congress, and an adjunct scholar at The Brookings Institution. She worked previously for Senate and House committees, including the Senate Select Committee to Study

the Senate Committee System. Schneider is a frequent speaker and lecturer on Congress and legislative procedures. She holds a bachelor's and master's degrees from The American University. Schneider is also co-author of the *Congressional Deskbook*, a comprehensive resource tool frequently used by Congress and lobbyists. She was a Stennis Fellow in the 108th Congress. Schneider is well known on Capitol Hill by Members of Congress, staff, lobbyists and others as "THE person" for information on numerous topics including House, Senate and Committee Procedure. Schneider was granted Emeritus Member status in Women in Government Relations in 2004. Emeritus Membership status is reserved for women who have displayed an exceptional commitment to helping other women succeed in the field of government relations, and who have also achieved notable personal success in that endeavor. Previously, only Members of Congress have been awarded this honor.

## **Tom Smith**

Adult Services & Outreach, Hydrocephalus Association  
San Francisco, CA

In 2002, Tom's father was diagnosed with NPH, thus beginning his association with the hydrocephalus community. Tom has been on the staff of the Hydrocephalus Association since 2007 and he's been a professional stand-up comedian since 2003. He is very happy to be attending his third Hydrocephalus Conference and humbled to be asked to present.

## **Stephen Trudeau, Ph. D.**

Thousand Oaks, CA

I am a licensed clinical psychologist and the father of a child with CP/Hydrocephalus. I have a full time clinical practice, co host a radio show on KCLU / NPR and give lectures and presentations on the challenges of special needs parenting. My son and I really enjoy motorcycling together on our sidecar motorcycle.

## **Diana Varela**

Social Security Administration

Public Affairs Specialist

Silver Spring, MD

Diana Varela is a Public Affairs Specialist for the Social Security Administration. She began her career with Social Security Administration as a Bilingual Service Representative in May 1995. She has held Claims Representative and Field Representative positions. She was appointed as a Bilingual Public Affairs Specialist in January 2003 to promote understanding of Social Security Programs in the Washington Metropolitan area.

## **Marion L. Walker, MD**

Primary Children's Medical Center

Salt Lake City, UT

Dr. Walker is Professor of Neurosurgery in the Division of Pediatric Neurosurgery/Department of Neurological Surgery and Adjunct Professor of Pediatrics at the University of Utah Health Sciences Center and the Primary Children's Medical Center in Salt Lake City, UT. His research interests are hydrocephalus and spasticity. He is a former Chairman of the Pediatric Section of the AANS, the Section on Pediatric Neurosurgery of the American Academy of Pediatrics and the American Society of Pediatric Neurosurgeons. He has served as President of the International Society of Pediatric Neurosurgery and is a past Editor of the Journal of Neurosurgery: Pediatrics. He is a founding member of the American Board of Pediatric Neurological

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Surgery and has served as the Chairman of that organization. He is currently Chairman of the Accreditation Council for Pediatric Neurosurgical Fellowships. Dr. Walker has been a member of the Medical Advisory Board for many years and currently serves as Chairman of the MAB. He joined the Board of Directors of the Hydrocephalus Association in 2008.

## **Benjamin Warf, MD**

Children's Hospital  
Boston, MA

Dr. Warf began his career in pediatric neurosurgery at Children's Hospital Boston in 1991 as the first Pediatric Fellow in Neurological Surgery. In 2000, he and his family moved to Uganda to help found a hospital for pediatric neurosurgery with CURE International, a non-profit Christian medical mission organization. While at CURE, Dr. Warf served as Medical Director and established the only pediatric neurosurgery hospital in Sub-Saharan Africa. Dr. Warf was the first to identify neonatal infection as the chief cause of pediatric hydrocephalus in a developing country and remains involved in working to uncover its pathogenesis in order to ultimately construct prevention strategies. He developed a novel surgical technique for treating hydrocephalus in infants, combining endoscopic third ventriculostomy with bilateral choroid plexus cauterization (ETV/CPC). Since returning to the United States, Dr. Warf has investigated the role of ETV/CPC in North American infants, and also continues to work in international neurosurgery development. He rejoined the team at Children's Boston in 2009, and was appointed Director of Neonatal and Congenital Anomaly Neurosurgery.

## **Michael A. Williams, MD**

LifeBridge Health Brain & Spine Institute  
Baltimore, MD

Dr. Williams is Medical Director of the Sandra and Malcolm Berman Brain & Spine Institute at Sinai Hospital of Baltimore. He was Chair of the AAN Ethics, Law and Humanities Committee from 2003-2009. He received his MD and Neurology training at Indiana University Medical Center, finishing in 1989. After a fellowship in Neurosciences Critical Care at Johns Hopkins Hospital, he joined the Department of Neurology faculty in 1991 where he was an NCCU attending physician and also established the Adult Hydrocephalus Center. He served on the Johns Hopkins Hospital Ethics Committee from 1992-2007, and was Co-Chair from 1999-2007. He was on the JHU Bioethics Institute Faculty from 1996-2007. He moved to Sinai Hospital in 2007 to become Medical Director of the Brain & Spine Institute, where he also established and directs their Adult Hydrocephalus Program. Dr. Williams' research and publications in hydrocephalus represent the systematic analysis of specialized clinical care, and include demonstration of best methods for diagnosing normal pressure hydrocephalus (NPH), evidence that there is significant recovery with treatment; descriptions of new syndromes such as SHYMA, the use of physiologic monitoring to diagnose hydrocephalus and related disorders, and demonstration of the national economic impact of treating or not treating NPH. He co-chaired the first-ever NINDS Workshop on hydrocephalus in 2005, and was on the steering committee for the 2009 NINDS and Hydrocephalus Association supported conference, "Improving outcomes in hydrocephalus: Bridging the gap between basic science and clinical management". In 2008, he helped create the International Society for Hydrocephalus and CSF Disorders (ISHCSF), hosted their first scientific conference in September 2009, and is currently the President-elect of the ISHCSF. He has either taught or been

director for courses related to hydrocephalus and disorders of intracranial pressure at the American Academy of Neurology (AAN) annual meeting for many years. He is actively involved in patient advocacy with the Hydrocephalus Association, and is a member of the Scientific Advisory Panel to the Intracranial Hypertension Research Foundation. While Chair of the AAN's ELHC, he led the development of updated AAN guidelines for the physician expert witness, an AAN position statement on laws and regulations concerning life-sustaining treatment, including artificial nutrition and hydration, and the addition to the AAN Code of Professional Conduct of a prohibition against neurologist participation in legally authorized executions. Since 2005, he has been the Associate Editor for Ethics for Continuum: Lifelong Learning in Neurology, the American Academy of Neurology's self-study continuing medical education publication. Dr. Williams has served on advisory committees for the Institute of Medicine, the U.S. Department of Health and Human Services, and the United Network for Organ Sharing. He has given invited lectures at the American Bar Association, the National Academy of Elder Law Attorneys, and at AAAS/Dana Foundation-sponsored Judicial Seminars on Emerging Issues in Neuroscience.

## **Robin Wilson, MD, Ph.D.**

LifeBridge Health Brain & Spine Institute  
Baltimore, MD

Robin K. Wilson, MD PhD, is a board certified neurologist and associate director of The Sandra and Malcolm Berman Brain & Spine Institute Adult Hydrocephalus Center in Baltimore, Maryland. She specializes in the diagnosis and management of adults with normal pressure hydrocephalus, secondary hydrocephalus, obstructive hydrocephalus, and congenital hydrocephalus.

## **Andrew Zabel, Ph.D., ABPP**

Kennedy Krieger Institute  
Baltimore, MD

Dr. Andrew Zabel is a pediatric neuropsychologist and research scientist at the Kennedy Krieger Institute. He is the clinical director of the Department of Neuropsychology and an assistant professor of Psychiatry and Behavioral Sciences at the Johns Hopkins School of Medicine. He is on the core faculty in psychology for the Maternal and Child Health Bureau (MCHB) Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disabilities (LEND) Program and the Mental Retardation and Developmental Disabilities Research Center (MRDDRC). Dr. Zabel received his doctoral degree in clinical psychology from Drexel University of Philadelphia, PA in 2000, and completed his internship training at the Kennedy Krieger Institute and Johns Hopkins University School of Medicine. Dr. Zabel also completed a two-year post-doctoral fellowship in pediatric neuropsychology at the Kennedy Krieger Institute and Johns Hopkins University School of Medicine. Dr. Zabel is board-certified in clinical neuropsychology by the American Board of Professional Psychology and is a licensed psychologist in Maryland. He joined the Hopkins/KKI faculty in 2002. He is active in the mentoring programs at the Kennedy Krieger Institute, and participates in the neuropsychological training of externs, pre-doctoral interns and post-doctoral residents. Dr. Zabel is the clinical director of the Department of Neuropsychology, and is active in the development of clinical services and provision of neuropsychological assessments at KKI.

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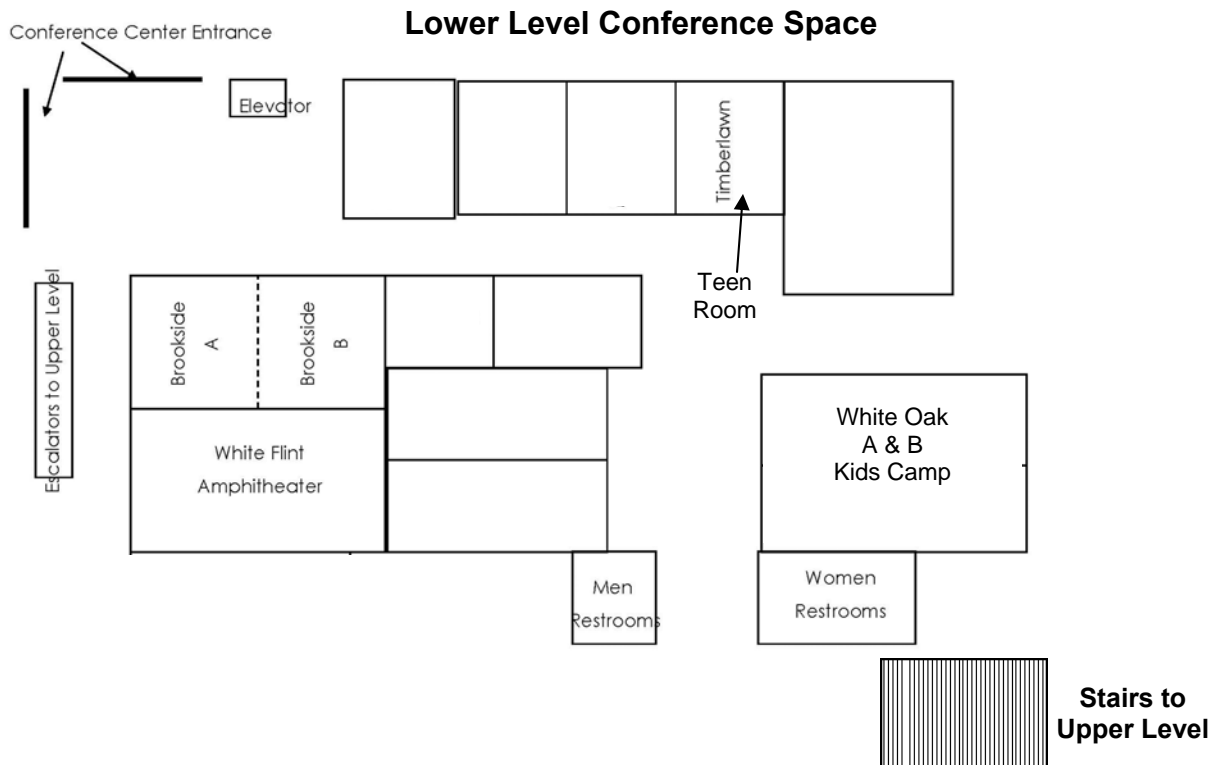
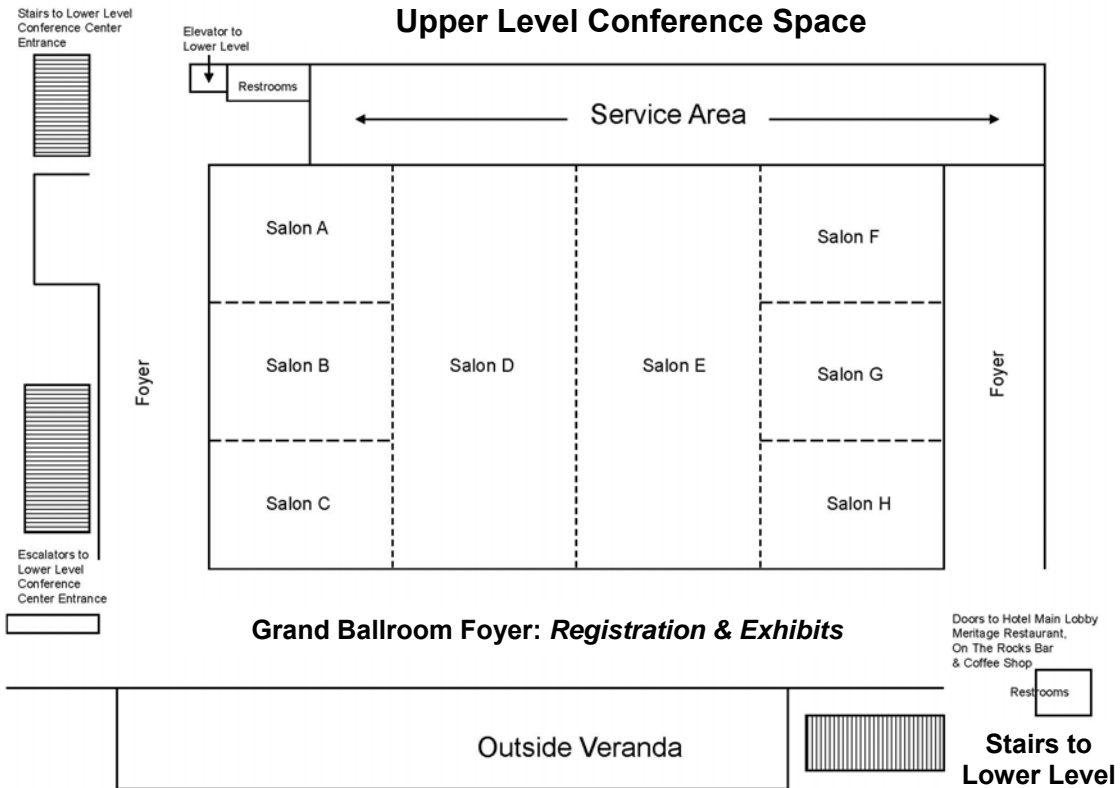
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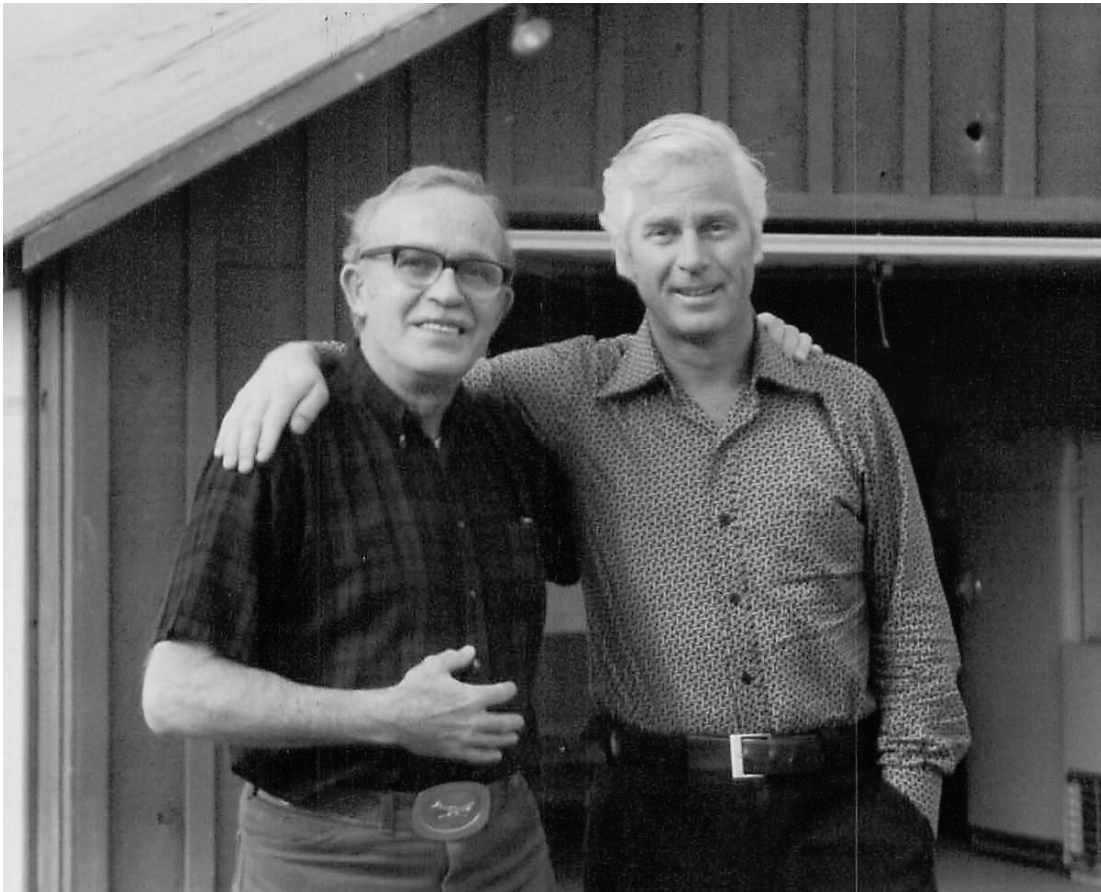
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# Conference Meeting Space Layout



## Dr. Robert Pudenz & Rudi Schulte



The Rudi Schulte Research Institute, a not-for-profit private operating foundation established in 1974 by Rudi Schulte, conducts studies to elucidate and seek improved treatments for hydrocephalus and other neurological disorders. Dr. Robert Pudenz, a long-time board member of the Institute, passed away in 1998. The Robert Pudenz Lectureship was established in 1999 to acknowledge Dr. Pudenz's work in the area of hydrocephalus and his overall contribution to the advances made in the diagnosis and treatment of pediatric neurological diseases.



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## SESSION EVALUATIONS

Please complete the session evaluation for each breakout session you attend. After the last group of sessions on Saturday afternoon, please tear out the evaluations from your booklet and hand them in at the conference registration desk.

### 100 Breakout Series: Select the session you attended:

- \_\_\_\_\_ Breakout Session 101: Families with Young Children Living with Hydrocephalus
- \_\_\_\_\_ Breakout Session 102: Parents of Children with Complex Hydrocephalus and/or Multiple Shunts
- \_\_\_\_\_ Breakout Session 103: Teens and Families of Teens
- \_\_\_\_\_ Breakout Session 104: Adults who were Treated in Childhood, including First Generation
- \_\_\_\_\_ Breakout Session 105: Adults Diagnosed in Young and Middle Age (SHYMA)
- \_\_\_\_\_ Breakout Session 106: Adults and their Families Affected by Normal Pressure Hydrocephalus

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

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- \_\_\_\_\_ Breakout Session 201: Selecting Patients for Endoscopic Third Ventriculostomy (ETV)
- \_\_\_\_\_ Breakout Session 202: Neuro-Urology
- \_\_\_\_\_ Breakout Session 203: Chiari and Syringomyelia (as it relates to hydrocephalus)
- \_\_\_\_\_ Breakout Session 204: Driving and Hydrocephalus
- \_\_\_\_\_ Breakout Session 205: Intracranial Hypertension (Pseudo Tumor Cerebri) and Ophthalmology
- \_\_\_\_\_ Breakout Session 206: Transition of Care - The Challenges for Teens and Young Adults

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

# SESSION EVALUATIONS

## **300 Breakout Series: Select the session you attended:**

- \_\_\_\_\_ Breakout Session 301: Insurance, SSI, Medicaid, Medicare
- \_\_\_\_\_ Breakout Session 302: Shunt Infections
- \_\_\_\_\_ Breakout Session 303: Neuropsychology and Older Adults (NPH and first generation congenital)
- \_\_\_\_\_ Breakout Session 304: HA Walks and Special Events: Are you ready to start an HA Fundraising event in your community?
- \_\_\_\_\_ Breakout Session 305: Headaches and Shunts, and the Medical Management of Headaches
- \_\_\_\_\_ Breakout Session 306: Measuring Outcome using the Hydrocephalus Outcome Questionnaire

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

## **400 Breakout Series: Select the session you attended:**

- \_\_\_\_\_ Breakout Session 401: Adolescents and Young Adults with Hydrocephalus: Neuropsychological Issues and Possible Solutions
- \_\_\_\_\_ Breakout Session 402: IF it's not NPH What is it?
- \_\_\_\_\_ Breakout Session 403: How to Start and Lead a Hydrocephalus Support Group in your Area
- \_\_\_\_\_ Breakout Session 404: SHYMA vs. LOVA - What Does This Mean?

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

# SESSION EVALUATIONS

## **500 Breakout Series:** *Select the session you attended:*

- ☐ Breakout Session 501: Pregnancy and Hydrocephalus
- ☐ Breakout Session 502: Cognitive Remediation and Neuropsychology
- ☐ Breakout Session 503: Teens Take Charge
- ☐ Breakout Session 504: Thinking your Way Through Difficult Medical Decisions
- ☐ Breakout Session 505: Spasticity and Gait Disorders in Adults and Children with Hydrocephalus

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

## **600 Breakout Series:** *Select the session you attended:*

- ☐ Breakout Session 601: ABCs of IEPs
- ☐ Breakout Session 602: The Role of Physiatry in the Care of Adults and Children with Hydrocephalus
- ☐ Breakout Session 603: Slit Ventricle Syndrome
- ☐ Breakout Session 604: Genetics and Hydrocephalus

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

# SESSION EVALUATIONS

## **700 Breakout Series: Select the session you attended:**

- ☐ Breakout Session 701: Shunt Building Workshop - Make Your Own Shunt!!
- ☐ Breakout Session 702: Workplace Communication Tips for People Living With Disabilities
- ☐ Breakout Session 703: Clinical Trials
- ☐ Breakout Session 704: Special Needs of Parenting

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

## **800 Breakout Series: Select the session you attended:**

- ☐ Breakout Session 801: NPH - When the Shunt no Longer Works
- ☐ Breakout Session 802: Special Need Trusts and Estate Planning
- ☐ Breakout Session 803: Laughing at the Elephant

**This session met my expectations:** ☐ above and beyond ☐ completely ☐ somewhat ☐ not at all

**This information was:** ☐ extremely useful ☐ very useful ☐ somewhat useful ☐ not useful

**The speaker was:** ☐ excellent ☐ good ☐ fair ☐ poor

**Overall impression:** ☐ excellent ☐ good ☐ fair ☐ poor

Additional Comments:

# OVERALL CONFERENCE EVALUATION

Please take a few minutes to complete the overall conference evaluation. Your response will help us design programs that will better meet your needs. Please check the best response for each question. When completed please tear out the evaluations from your booklet and hand them in at the conference registration desk.

**The information presented during the conference was:**

☐ Too complex      ☐ Just right      ☐ Too basic

**The conference facility was comfortable:**

☐ Strongly Agree      ☐ Agree      ☐ Undecided      ☐ Disagree      ☐ Strongly Disagree

**The length of the conference was:**

☐ Too long      ☐ Just right      ☐ Not long enough

**I received new and helpful information at the conference:**

☐ Strongly Agree      ☐ Agree      ☐ Undecided      ☐ Disagree      ☐ Strongly Disagree

**Which conference subject matter was most valuable to you?**

*Please rank 1 (most valuable) - 6 (least valuable)*

- Transition of Care
- Medical/Clinical (Includes Shunt Surgery, Neuropsychology, etc.)
- Future and Financial Planning
- Adults (living with hydrocephalus)
- Research
- Parenting
- Meeting peers in the interpersonal sessions

**What were the most important considerations when you decided to attend the conference?**

*Please rank 1 (most important) - 9 (least important)*

<input type="checkbox"/> Child-Friendly City	<input type="checkbox"/> Hotel Room Rate	<input type="checkbox"/> Destination Easily Reached
<input type="checkbox"/> Conference Session Descriptions	<input type="checkbox"/> Speakers	<input type="checkbox"/> Dates
<input type="checkbox"/> Lots of Attractions	<input type="checkbox"/> Registration Cost	<input type="checkbox"/> Other: _____

**(Continued →)**

# OVERALL CONFERENCE EVALUATION

## Where do you get most of your information on Hydrocephalus?

Please rank in order of your preferred method of obtaining information.

1 (preferred method) – 7 (least preferred method)

- \_\_\_ HA Website
- \_\_\_ HA Support Phone Line
- \_\_\_ Social Media Sites: Face Book, Twitter
- \_\_\_ Internet in general
- \_\_\_ Chat rooms or ListServes dedicated to Hydrocephalus
- \_\_\_ Clinic, Health Professional or Healthcare Provider
- \_\_\_ Support Group meetings, Walk Events held by HA
- \_\_\_ Other (please specify)

## As a whole, my goals in attending the 12<sup>th</sup> National Conference on Hydrocephalus were achieved:

☐ Strongly Agree      ☐ Agree      ☐ Undecided      ☐ Disagree      ☐ Strongly Disagree

## How likely are you to attend the 13<sup>th</sup> National Conference on Hydrocephalus in 2014?

☐ Definitely attending!      ☐ Very likely      ☐ Possibly      ☐ Unlikely      ☐ Not attending

## Please give us your ideas about where you would like us to hold a future HA National Conference.

Please rank in order of your preferred region. 1 (preferred region) – 6 (least preferred region)

\_\_\_ Northeast      \_\_\_ Southeast      \_\_\_ Mid-Atlantic      \_\_\_ Mid-West  
\_\_\_ Southwest      \_\_\_ Northwest      \_\_\_ Specific Location \_\_\_\_\_

What did you like most about the conference?

What did you like least about the conference?

In what ways could the HA conference be improved in the future?

Additional Comments:



## NOTES

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## NOTES

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## NOTES

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