



EDUCATION DAY 2011: BUILDING COMMUNITY

May 7, 2011

8:00 a.m. - 4:00 p.m

UC Denver Anschutz Campus Education 1 Building



University of Colorado
Anschutz Medical Campus

School of Medicine
Hemophilia and Thrombosis Center

Baxter

biogen idec

HEMOPHILIA

 **CORAM.**
specialty infusion services
An Apria Healthcare Company

CSL Behring

Biotherapies for Life™

EDUCATION DAY SCHEDULE

8:00 – 8:30	Registration & Expo Booth Bingo
8:45 – 10:00	Keynote Presentation
10:00 – 10:45	HSC Annual Meeting
11:00 – 12:00	Concurrent Morning Breakout Sessions
12:00 – 1:30	Box Lunch Discussions & Expo Booth Bingo
1:30 – 2:30	Concurrent Afternoon Breakout Sessions
2:30 – 4:00	Honoring Dr. Hathaway, HTC Open House, and Social Event

	Session 1	Session 2	Session 3	Session 4	Session 5
Morning (11:00 a.m. - 12:00 p.m.)	Exercise for Health Joints	HTC Update (Spanish & English)	The Financial Factor: Managing the Costs of Hemophilia	Facts First: School Advocacy (Spanish)	Long Lasting Coagulation Factors for Hemophilia A and B
Afternoon (1:30 p.m. - 2:30 p.m.)	Kids' Program- ming	HTC Update (Spanish & English)	Facts First: Inhibitors	Facts First: Ask the Doctor (Spanish)	You Can Make a Difference! Grassroots Advocacy and Outreach

EXPO BOOTH BINGO

Many many thanks to our Education Day 2011 exhibitors! Without your participation, Education Day would not be possible. Each Education Day participant has been given a “booth bingo” card. Here are the instructions for the game:

1. Stop by as many sponsor expo booths through out the Education Day and learn more about the companies represented.
2. Collect a company stamp on your booth bingo card (provided in your program packet). The goal is to complete the entire booth bingo card with stamps. Those with completely stamped cards will be entered for a drawing at the HTC Open House.
3. Stop by the registration desk before the HTC open house and drop off your completed card.
4. At the HTC Open House Social, HSC will announce the Booth Bingo winners and share their prizes!

Thank you to all of our supporters!!!



Accredo

Bayer

BioRx

Novo Nordisk

ARJ Infusion

Grifols

Pfizer

KEYNOTE PRESENTATION

Offered in Spanish and English

8:45 a.m. - 10:00 a.m.



University of Colorado
Anschutz Medical Campus

School of Medicine
Hemophilia and Thrombosis Center

Why Can't Every Day be Mother's Day?

In 2010, National Hemophilia Foundation launched the new Victory for Women Project at their Annual Meeting in New Orleans. Victory for Women with Bleeding Disorders is an endeavor that enhances the efforts of Project Red Flag by incorporating education, advocacy, and support for women diagnosed with a blood disorder and raises awareness among women have not yet been diagnosed. Women are such a critical part of our community - they are our mothers, sisters, aunts, friends, girlfriends and spouses.

Join us for this special keynote presentation by former HTC nurse, Ruth Ann Kirschman, where she will share more about the Victory for Women Project; women who are affected by bleeding disorders; why this is such an important issue; and how to empower, recognize, and listen to women from the bleeding disorder community.

About Ruth Ann Kirschman

Ruth Ann has been a nationally certified Women's Health Nurse Practitioner for the past 30 years. She has practiced in public health settings and private practices. She is currently completing a master's degree in women's healthcare at the University of Colorado Health Sciences Center.

Ruth Ann was previously employed by the Mountain States' Regional Hemophilia and Thrombosis Center (HTC) as a nurse practitioner/research associate for persons with bleeding and clotting disorders. Ruth Ann is a member of the national Women with Bleeding Disorders Task Force for the National Hemophilia Foundation, which provides input to the NHF chapters and hemophilia treatment centers on women's issues related to bleeding disorders and continues to build the NHF Victory for Women program.

She is on the planning committee for the NHF annual meeting to be held in Chicago, November 10-12, 2011. Further in the area of women's health, Ruth Ann serves as immediate past chairman of the board of the Lupus Foundation of Colorado, another area of health concern for women. She is the mother of two grown children and "Nana" to two grandchildren. Her interests are running, fly fishing, reading and improving her cooking skills.

HSC ANNUAL MEETING

Offered in Spanish and English

10:00 a.m. - 10:45 a.m.

Join us for the HSC Annual Meeting following the keynote presentation to hear about what has been happening at The Society as presented by the new HSC Executive Director, Emily Davis. Learn about HSC programs, improved services to the community members, plans for the future of the chapter, and how you can get involved.

CONCURRENT MORNING BREAKOUT SESSIONS

Session 1: Exercise for Health Joints

Jeff Kallberg, PT

11:00 a.m. - 12:00 p.m.



This session will be set in a fun, motivational setting on the importance of exercise for healthy joints. In addition to providing practical advice and helpful tips on stretching and exercise, Jeff shows outcomes from actual hemophilia patients he has worked with to help restore lost mobility and range of motion. He maintains that for many patients, giving in to limited joint mobility to some extent, is a choice and can be avoided with proper motivation and training.

About Jeff Kallberg, PT

Jeff Kallberg (42) specializes in physical therapy and physical fitness for people who have hemophilia and bleeding disorders and has severe hemophilia himself. He received his degree in Physical Therapy from the University of Minnesota in 1994 and has worked in many settings and with patients of all ages and diagnosis before settling in to his own private practice in Savage, MN. Jeff speaks on the topic of physical fitness and managing the problems associated with hemophilia across the country and has been featured in NHF's HemAware magazine. He is also a black belt in tae kwon do, trains in various martial arts and uses exercise to manage his own joint problems. He has developed a program at Accua in Savage MN to provide specialized PT and fitness services to our population using state-of-the-art equipment and facilities.

Session 2: HTC Update

Dr. Michael Wang

11:00 a.m - 12:00 p.m.

Offered in Spanish and English



The Hemophilia & Thrombosis Center (HTC) has relocated to a new building near the UC Denver Anschutz Medical Campus. There are important and exciting updates to share with HTC patients. More importantly this will be a time to meet Dr. Wang, and ask questions about the future of the HTC as it moves forward. The HTC is dedicated to continue providing the best care possible for patients and families, and sees this as an ideal time to focus a discussion about the specific needs and concerns of the hemophilia community. There is a morning and an afternoon session, both offered in Spanish and English, to help answer all of your questions and inform you and your family about changes related to the HTC.

About Dr. Michael Wang

Dr. Michael Wang is board certified in Pediatrics and Pediatric Hematology-Oncology and is the Clinical Director for the UC Denver Hemophilia & Thrombosis Center (HTC), and Staff Physician at the Center for Cancer & Bleeding Disorders, The Children's Hospital and the University of Colorado Hospital. Dr. Wang is also an Assistant Professor for Pediatrics at UCD School of Medicine. Dr. Wang received his undergraduate degree from Colorado College and his medical degree from the University of Rochester School of Medicine and Dentistry. His residency was conducted at the University of Utah, Primary Children's Medical Center in Pediatrics, and Fellowship at UCD/The Children's Hospital in Hematology/Oncology/BMT.

Session 3: The Financial Factor: Managing the Costs of Hemophilia

Marianne McDaniel, Children's Hospital of Orange County

11:00 a.m. - 12:00 p.m.

The Financial Factor: Managing the Costs of Hemophilia has been developed to help families understand the financial implications of a diagnosis of hemophilia, the importance of finding and retaining good insurance coverage, the available resources for handling insurance and reimbursement issues and the need to plan for the future. Families caring for patients with hemophilia should know that the financial future is brighter with the recent passage of the Patient Protection and Affordable Care Act (PPACA) on March 23, 2010.



The PPACA has several provisions in it that take effect in 6 months on September 23, 2010, which will be helpful to families caring for patients with hemophilia. For example, the act

prohibits discrimination against children with pre-existing conditions, bans insurance companies from dropping people from coverage when they get sick, extends coverage for young people up to their 26th birthday through their parents' insurance policy and bans lifetime limits and restrictive annual limits on coverage.

Session 4: Facts First: School Advocacy

Clemencia Casas-Byots

11:00 a.m. - 12:00 p.m.

Offered in Spanish

Clemencia Casas-Byots, Bilingual Health Educator from Baxter and Erin Stang, social worker from University of Colorado Denver, Hemophilia and Thrombosis Center, will conduct this session in Spanish. The purpose of this presentation is to show parents and students with hemophilia how they can take responsibility for the success of their education by collaborating with school personnel and their Hemophilia Treatment Center by:

- ◆ Learning how to educate school personnel about hemophilia so they can more effectively prepare for children's educational and healthcare needs.
- ◆ Identifying the roles and responsibilities of students, parents, Hemophilia Treatment Center and school personnel so they can improve educational outcomes.
- ◆ Understanding the laws that assure students with hemophilia equal access to education.

About Clemencia Casas-Byots

Clemencia Casas-Byots is a Bilingual Health Educator for Baxter Bioscience with over 30 years of experience in working with the Hispanic community. As a Hispanic Parent Educator, she has worked with various communities, medical and state based programs to create and enhance educational, cultural, and health outreach services to the Hispanic community in the Midwestern United States.

The Baxter logo is displayed in a bold, blue, italicized sans-serif font.

Session 5: Long Lasting Coagulation Factors for Hemophilia A & B

Dr. Glenn Pierce, MD, PhD, Senior Vice President and Chief Medical Officer

11:00 a.m. - 12:00 p.m.

This session will provide a summary of the research being conducted by medical centers and the industry on longer lasting hemophilia factors, and a summary of the status of those projects. There will be slides on the science of each of the longer lasting products, and a time for questions and answers.



About Dr. Glenn Pierce

Dr. Pierce joined Biogen Idec's hemophilia therapeutic area in 2009, from Bayer Healthcare, Bayer Schering Pharma where he was Scientific Head, US Research Center and Vice President, Applied Research Hematology. He has more than 20 years of experience in biotechnology research and development, from the bench to the bedside in small, large, public and private biotech/biopharma firms, including Avigen, Selective Genetics, and Amgen. He is the co-author of over 150 scientific papers, has more than 9 U.S. patents, and is a member of numerous medical and scientific groups including the WFH, NHF, ISTH, and ASH. Dr. Pierce served on the Blood Products Advisory Committee at the Food and Drug Administration and served on the Medical and Scientific Advisory Council, the Board of Directors and was President of the Board of the National Hemophilia Foundation. Dr. Pierce also served on the Committee on Blood Safety and Availability at the Department of Health and Human Services. Dr. Pierce received an M.D. and a Ph.D. in Experimental Pathology, both from Case Western Reserve University in Cleveland, Ohio and did his postgraduate training at Washington University in St. Louis.

LUNCH TABLE DISCUSSION TOPICS

12:00 p.m. - 1:30 p.m.

HSC will provide box lunches for all participants. Many of the tables are designated for particular table discussion topics. Below you will see a list of the table discussion topics and are encouraged to join a discussion topic that appeals to you. Don't forget to join in on the Expo Booth Bingo to be eligible for a give-away during the HTC Open House! Kids ages 3 - 10 will meet in session room 1 for lunch and a movie.

Parents Empowering Parents (PEP) Table

Hosted by Erin Stang, HTC



Come and learn about the Parents Empowering Parents (PEP) Program.

PEP is a program designed to promote effective parenting skills to parents of children with bleeding disorders through education and support. Why is PEP so valuable to parents? Raising a child with a genetic bleeding disorder is a significant challenge that impacts the entire family. The PEP program was designed to address this need by affirming positive parent/child behaviors while focusing on the unique problems faced by parents of children with bleeding disorders.

Hemotivo Table

Spanish-speaking

Hosted by Guillermo Campillo & Anna Clark



This table discussion will cover resources available in Colorado and nationally in terms of support, education, medical resources, and financial assistance for the Spanish-speaking community. We will discuss national (NHF) and (HSC, HTC, Hemotivo) local resources including brainstorming the needs/interests/concerns of the Latino/Hispanic community. This discussion will be presented in Spanish, uniquely for the Latino/Hispanic community.

Own Your Bleeding Disorder: Being Responsible

Hosted by Bonnie Webb, Customer Account Manager, Accredo HHS

At Accredo HHS we believe in educating and empowering our clients to own their bleeding Disorders. Responsibility is the key.



Healthcare Reform Today Table

Offered in Spanish and English

Hosted by Elizabeth Stoltz, Senior Manager, Reimbursement and Advocacy

This discussion will serve as a means for people in the hemophilia community to get real answers to their questions about the changing



healthcare landscape - from general questions about new rules and regulations to specific queries about individual situations.

Future Therapies for Hemophilia Table

Hosted by Dr. Glenn Pierce, MD, PhD, Senior Vice President and Chief Medical Officer



School Preparedness Kit Table

Hosted by Debbie Costales & Adrienne Smith, Coram Consumer Advocates
Available in Spanish

Coram's School Preparedness Kit is a template that should be used as a guide to help parents and schools prepare an Individualized Health Plan for a child with hemophilia or a related bleeding disorder. This sample plan should be used in working with the child's physician, hemophilia treatment center (HTC) and appropriate school personnel.



Prophylaxis: Valuable lessons from the Joint Outcome Study

Hosted by Steven Petty, Bayer Hematology Account Specialist



Product Safety, Foundation of Quality-Ask me about the Four Pillars of the Safety System

Hosted by Kent Pointer, CSL Behring Coagulation Products Manager



Additional tables hosted by...



CONCURRENT AFTERNOON BREAKOUT SESSIONS

Session 1: Kids Programming

1:30 p.m. - 2:30 p.m.

Special programs and activities for kids 3 - 10 including a visit from the Butterfly Pavilion!

Session 2: HTC Update

Dr. Michael Wang

1:30 p.m. - 2:30 p.m.

Offered in Spanish and English



The Hemophilia & Thrombosis Center (HTC) has relocated to a new building near the UC Denver Anschutz Medical Campus. There are important and exciting updates to share with HTC patients. More importantly this will be a time to meet Dr. Wang, and ask questions about the future of the HTC as it moves forward. The HTC is dedicated to continue providing the best care possible for patients and families, and sees this as an ideal time to focus a discussion about the specific needs and concerns of the hemophilia community. There is a morning and an afternoon session, both offered in Spanish and English, to help answer all of your questions and inform you and your family about changes related to the HTC.

About Dr. Michael Wang

Dr. Michael Wang is board certified in Pediatrics and Pediatric Hematology-Oncology and is the Clinical Director for the UC Denver Hemophilia & Thrombosis Center (HTC), and Staff Physician at the Center for Cancer & Bleeding Disorders, The Children's Hospital and the University of Colorado Hospital. Dr. Wang is also an Assistant Professor for Pediatrics at UCD School of Medicine. Dr. Wang received his undergraduate degree from Colorado College and his medical degree from the University of Rochester School of Medicine and Dentistry. His residency was conducted at the University of Utah, Primary Children's Medical Center in Pediatrics, and Fellowship at UCD/The Children's Hospital in Hematology/Oncology/BMT.

Session 3: Facts First: Inhibitors

MaryKay Thrower, RN

1:30 p.m. - 2:30 p.m.



In the Inhibitors session we will cover three main topics related inhibitors affecting those with bleeding disorders: understanding and identifying inhibitors, assessing the risk factors, and management of inhibitors. This presentation on Inhibitors is part of the larger

Facts First programming that Baxter offers hosted by live clinicians, national advocates, and industry experts. These educational programs enable participants to connect and learn about a range of relevant topics.

About Marykay Thrower

Marykay Thrower is a Senior Clinical Specialist in Hemophilia for Baxter Bio Science. She has had over 20 years experience in Hemophilia.. She was the Nurse coordinator at the Pediatric HTC in St. Louis from 1990 til 2005. During her years at the HTC she served on the National Hemophilia Foundation's Nursing Working Group; served on the planning committee for the National Hemophilia Foundation National meeting, served as one of the Editorial reviewers for HemAware, she also served as a member of the MO Department of Health Genetics committee on Hemophilia.

Session 4: Facts First: Ask the Doctor

Dr. Jorge DiPaola, Associate Professor of Pediatrics and Genetics,
The Postle Family Chair in Pediatric Cancer and Blood Disorders,
University of Colorado, Denver

1:30 p.m. - 2:30 p.m.

Offered in Spanish

The Baxter logo is displayed in a bold, blue, sans-serif font.

During this interactive session Dr. Di Paola will review the basics concepts of Hemophilia, including but not limited to the diagnosis, genetic, inhibitor development and the treatment of hemophilia. Additional key points of discussions will help participants identify the different types and consequences of bleeding episodes as well treatment options.

About Dr. Jorge DiPaola

Jorge DiPaola received his MD from the University of Buenos Aires in Argentina. He then completed a residency in Pediatrics at the National Pediatric Hospital in Buenos Aires. Upon moving to the United States in 1995, he completed a second pediatric residency and a pediatric hematology-oncology fellowship at the Children's Hospital of Orange County, in Orange, California.

In 2000, he became a faculty member and Director of the Hemophilia and Thrombosis Center at the University of Iowa. He was appointed Associate Professor of Pediatrics with tenure in 2007. In 2008, he moved to the University of Colorado in Denver where he is an Associate Professor of Pediatrics and Genetics and Director of Basic and Translational Research in Hemostasis in the Section of Pediatric Hematology/Oncology and BMT. He holds the Postle Family Chair in Pediatric Cancer and Blood Disorders.

Dr DiPaola's research focuses on the genetics of von Willebrand Disease and platelet disorders. Dr DiPaola's research has been continuously funded by the National Institute of Health since the year 2001, and he is a permanent member of the Hemostasis and

Thrombosis Study Section at NIH. He is Vice-President/President elect of the hemophilia and Thrombosis Research Society. In the clinical setting, Dr DiPaola cares for patients with bleeding and thrombotic disorders at the Mountain States Hemophilia and Thrombosis Center of the University of Colorado.

Session 5: You Can Make a Difference! Grassroots Advocacy and Outreach



Kim Isenberg, Senior Manager, State Government Affairs, CSL Behring
1:30 p.m. - 2:30 p.m.

CSL Behring believes that successful advocacy results from the empowerment of those that are impacted by a particular issue. Many policy makers who determine access to care for those who rely on plasma-derived and recombinant therapies know very little about bleeding disorders. Establishing awareness starts with you. You have the power to positively impact your future through advocacy.

This instructional overview will provide you with tips, tools and useful information of how you as a member of the Hemophilia Society of Colorado can participate in the legislative process and have a positive impact on public policy.

About Kim Isenberg

Kim is an accomplished executive with a flair for advancing the objectives of corporate, community and government leaders through strategic communications that encompass vision, values and shared interests. She delivers a rare combination of corporate communications, public affairs/issues management and media relations expertise. As the Senior Manager for State Government Affairs, Kim oversees CSL Behring's state legislative and regulatory activities.

Prior to joining CSL Behring, Kim was a senior consultant for various Minneapolis-based public relations agencies, where she developed and executed major issues-based campaigns for a number of Fortune 500 companies. She also served as regional director for government affairs at the Pharmaceutical Research and Manufacturers of America (PhRMA), responsible for government relations, grassroots and media relations for the industry in eight states; directed public affairs at the Metropolitan Council, the Twin Cities region's planning authority; and served as policy staff for the University of Minnesota Board of Regents.

KIDS' ACTIVITY SCHEDULE

AGES	TIME	ACTIVITY	LOCATION
Young Adults (ages 11 - 16)	8:00 - 8:30 a.m.	Drop off for service project	Room P26 1306
Young Adults (ages 11 - 16)	8:45 a.m.	Load bus for service project	TBA
Young Adults (ages 11 - 16)	9:00 a.m. - 12:00 p.m.	Bluff Lake Nature Center Service Learning Project	Havana Way, Denver 80238
Young Adults (ages 11 - 16)	12:00 - 1:30 p.m.	Return to UCD. Lunch and clean up	TBA
Young Adults (ages 11 - 16)	1:30 - 2:30 p.m.	Grassroots Advocacy session	P26 1105
Young Adults (ages 11 - 16)	2:30 p.m.	Pick up for HTC Open House	P 26 1306

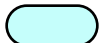

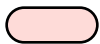
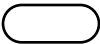
AGES	TIME	ACTIVITY	LOCATION
Kids (ages 3 – 10)	8:00 – 8:30 a.m.	Drop off for activities	Room P26 1306
Kids (ages 3 – 10)	8:30 a.m. – 12:00 p.m.	Kids Activities!	TBA
Kids (ages 3 – 10)	12:00 – 1:30 p.m.	Lunch and a Movie!*	P 26 1100 (Session #5 Room)
Kids (ages 3 – 10)	1:30 p.m. – 12:30 p.m.	Kids Activities!	TBA
Kids (ages 3 – 10)	2:30 p.m.	Parents pick up kids for HTC Open House	P 26 1306

Note to parents: Kids have activities planned separately from the lunch discussions. No need to pick them up.

AGES	TIME	ACTIVITY	LOCATION
Infants (ages 0 – 3)	8:00 – 8:30 a.m.	Drop off at nursery	Room P26 1106
Infants (ages 0 – 3)	2:30 p.m.	Pick up for HTC Open House	P 26 1106

ENTRANCE

EDUCATION DAY 2011 MAP

-  Programming
-  Expo & Booth Bingo
-  Kids Activities
-  Open - no programs

EXPO AND BOOTH BINGO AREA

NURSERY

SESSION 5
(P26 1105)

SESSION 4
(P26 1103)

SESSION 3
(P26 1102)

SESSION 2
(P26 1101)

SESSION 1
(P26 1100)

KIDS
ACTIVITIES
P26 1209 -
P26 1204

P26 1200 -
P26 1203

RESTROOMS

REGISTRATION
(P26 1308)

(P26 1307)

KIDS PICK UP
& DROP OFF
(P26 1306)

P26 1305-1301

KEYNOTE
(P26 1300)

BOX LUNCH AND TABLE DISCUSSIONS