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Children's Medical Center of Dayton Factor Infusion Program
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THE 2007



CARNIVAL IN COLUMBUS

AUGUST 3RD THROUGH 5TH
COLUMBUS CROWNE PLAZA
NORTH

OFFICIAL PROGRAM

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University of Cincinnati Factor Program
[A provider of factor clotting concentrates and supplies]
231 Albert Sabin Way
Cincinnati, OH 45267
513.584.7639

Friends Level
Nationwide Insurance

Children's Medical Center of Dayton Factor Infusion Program
[Factor Products]
One Children's Plaza
Dayton, OH 45404
937.641.5428

Coalition for Hemophilia B
[Provides information, education and support to consumers with hemophilia B and their families]
451 East 83rd St, No. 4D
New York, NY 10028
hemob@ix.netcom.com

Factor Health Management
[Clotting Factor and Home Health Services]
7700 Congress Ave Suite 3109
Boca Raton, FL 33487
866.322.3461

Grifols Biologicals US
[Plasma Derived Factor Products. Alphanate, Alphanine, Profilnine]
2410 Lillyvale Ave
Los Angeles, CA 90032
888.325.8579
grifolsusa.com

Hemophilia Health Services
[Factor Care Services with all Coagulation Products, Supplies, therapy management and community support]
6820 Charlotte Pike
Nashville, TN 37209
800.800.6606

Matrix Health Group
[Healthcare Management providing Comprehensive Pharmacy, Education, and Specialized clinical support to the bleeding disorders community]
3300 Corporate Ave
Suite 104
Weston, FL 33331
877.337.3002

Novo Nordisk
[Novo Seven, rFV11a]
30146 Washington Way
Westlake, OH 44145
440.899.0377

NuFACTOR
[Specialty Homecare Services and Specialty Pharmacy]
41093 County Center Drive
Temecula, CA 92591
Nufactor.com
800.323.6832

University Option Care
Local branches available in Milford, OH (513)576-8400
Dayton, OH (937)290-0530 Crestview, KY (859)331-8500 and in
Central Ohio at 445 E Dublin-Granville Road, Building R
Worthington, OH 43085
614.293-2273 800.243.1090

SCHEDULE OF EVENTS

Friday, August 3rd

3:00—8:30 p.m.	Registration Opens	<i>Capital Room</i>
4:00 p.m.	Hotel Check-In	<i>Front Desk</i>
3:00—9:00 p.m.	Meet and Greet Resource Room	<i>Main Ballroom</i>
<i>Including 3 Shows by Ventriloquist Denny Baker at 4:30, 6:30 and 8:30 p.m. for the kids; Information and socializing for the adults</i>		
5:00—9:00 p.m.	Outdoor Fun	<i>Pool Area</i>
6:00—9:00 p.m.	Heavy Appetizers	<i>Main Ballroom</i>

Saturday, August 4th

7:00—9:00 a.m.	Breakfast	<i>Main Ballroom</i>
<i>Welcome Remarks at 8:45 a.m.</i>		
8:00—9:30 a.m.	Saturday Registration	<i>Capital Room</i>
9:00 a.m.—3:00 p.m.	Women's Comfort Room	<i>Cardinal Room</i>
9:00—9:30 a.m.	Child Care Registration	
Infants 6 mos. To 2 yrs. <i>Suites 325 and 340</i>		
Children 3-6 yrs. <i>Salons D, E, F & Executive Boardroom</i>		
Youth 7-12 yrs. <i>Salons A, B, C</i>		
Teen 13-17 <i>Room 225</i>		
9:00—10:00 a.m.	Exhibits Open	<i>Foyers 1&2</i>
10:00—11:30 a.m.	Educational Sessions	<i>Ballrooms I-IV</i>
School Panel: Shooting for the Stars! <i>Ballroom I</i>		
Transition Issues/Financial <i>Ballroom II</i>		
HEP C <i>Ballroom III</i>		
Hemophilia 101 <i>Ballroom IV</i>		
11:45 a.m.	Pick Up Infants	
12:00—1:30 p.m.	Lunch	<i>Main Ballroom</i>
1:45—2:45 p.m.	Educational Sessions	<i>Ballrooms I-IV</i>
Exercise, Sports and Health <i>Ballroom I</i>		
Women with Bleeding Disorders/Jeopardy <i>Ballroom II</i>		
Stress Management <i>Ballroom III</i>		
Advocacy/Changes to Ohio Medicaid and BCMH <i>Ballroom IV</i>		

SCHEDULE OF EVENTS, CONT.

- 1:30 p.m. **Infants Return to Program**
- 2:45-3:00 p.m. **Break**
- 3:00—4:15 p.m. **Rap Sessions: Q&A, Discussion *Ballrooms I-IV***
 - Men Only (including fathers) *Ballroom I*
 - School-Aged *Ballroom II*
 - Infants/Preschool *Ballroom III*
 - Teen *Ballroom IV*
- 4:30 **Child Care Closes**
- 4:30 **Exhibits Close**
- 6:00 p.m. **Dinner and Family Carnival Night *Ballroom & Pavilion***

Including 12 kid-friendly carnival games, 2 card tables, 2 bingo tables, a family-friendly DJ and roaming dinner stations! Prizes for everyone!!

Sunday, August 5th

- 8:30—10:30 a.m. **Breakfast & Programming**
Including annual awards presentations, re-cap of weekend slideshow and photos for families to take home!
- 11:00 a.m. **Adjourn Weekend**

FAMOHIO Board Members

- Coy White, President
- Teresa Bridges, Past President
- Madeline Heffner, B.S.N., Secretary
- Monica Snider, Alternate Secretary
- Elizabeth Billow, L.I.S.W., Vice President/Planning
- Rick Sites, J.D., M.S., Vice President/Legal
- Les Gutter, C.P.A., Treasurer
- Charmaine Biega, R.N.
- Pat Burkey, R.N.
- Linda Casto, MSW
- Randy Clites
- Laura English
- Marjorie Gaffin, L.I.S.W.
- Gloria Gutter, R.N.

BioRx
[Specialty Pharmacy Home Care Provider]
10828 Kenwood Road
Cincinnati, OH 45242
866 44BIORX

Cincinnati Children's Hospital Factor Program
[Home Health care. Factor Products and Supplies]
615 Elsinore Place
Cincinnati, OH 45202
513-636-4663 513 636 5341 fax

Columbus Children's Home Factor Program
[home factor services]
700 Children's Drive
Columbus, OH 43205
614 722 6312

Coram Hemophilia Services
[Factor Therapy, Home infusion Services and specialty pharmacy distribution with 70 branches across the county]
6 Spring Mill Drive
Malvern, PA 19355
304 610 0942 or fax to 610 578 1698

Critical Care Systems
[Personalized Service, community based advocacy, education & support for the bleeding disorders community]
61 Spit Brook, Suite 505
Nashua, NH 03060
603.888.1500

CSI Infusion Services
[All Factor products and support for local community programs]
6955 Treeline Drive
Brecksville, OH 44141
877.234.9564

CSL Behring, L.L.C..
[Monoclote-P, Mononine, Humate-P, HelixateFS, Stimute]
1020 First Avenue
King of Prussia, PA 19406
610.878.4000

2007 MAJOR BENEFACTOR DIRECTORY

Platinum Level

Baxter Bioscience
[ADVATE, Recombinate, FEIBA, Hemofil-M]
One Baxter Parkway
Deerfield, IL 60015
800.241.9360

Cascade Hemophilia Consortium
[Provider of Hemophilia/HIV/Hepatitis Medications & Services]
210 East Huron, Suite D
Ann Arbor, MI 48104
800.996.2575 & fax 734.996.5566

Gold Level

Wyeth Hemophilia
[Refacto \ BeneFix]
555 E Lancaster Ave
St Davids, PA 19087
888.440.8100

Silver Level

Caremark
[Special Pharmacy providing a full array of blood clotting factors and medically necessary supplies]
1127 Bryn Mawr Ave
Redlands, CA 92374
800.225.5967

Bronze Level

Akron Children's Factor Program
[Home Care Factor Delivery service]
One Perkins Square
Akron, OH 44308
330 543 3513

Bayer Healthcare
[Kogenate with Bio Set]
2313 Highland Ave
Allison Park, PA 15101
412. 487. 3948

WELCOME FROM THE PRESIDENT

I want to extend a welcome to all those attending our 15th annual meeting. As president, one thing I have learned is that you need to repeat yourself from time to time to be sure you're being heard. When we first got together in 1992, we hoped to repeat. We didand then again, and have kept it going from there. The event may change in format now and then, and we may focus on different issues that need to be discussed, but there is value in learning from each other every year. Some years the discussions at our event are almost urgent. There will also be events where the most important thing you get from the meeting is a phone number of a good friend. It's all valuable.

Our goal every year is to address topics that are current to our community. These issues concern government, schools, insurance, treatment options and a myriad of other topics. A class, a lecture or a teacher can provide you with the information to empower you, but only a friend can make sure you realize you are not alone and that others have gone down similar roads and succeeded. As always we have tried to keep our schedule open enough for you to visit families and friends within the community. We certainly encourage you to attend all the sessions you can and also to take every opportunity to reunite with friends.

Last year I told you that we would be trying new things. And this year, after hearing your feedback, we have given Friday a more active schedule. Your input is critical. There are various ways of getting your thoughts and opinions to our meetings. The best idea would be for you to attend some of our Planning Committee meetings. You may not make them all, but your voice would be heard. All of us involved in planning are committed to the idea that FAMOHIO will not and cannot continue to repeat year after year without the input of fresh ideas, new questions and invigorated volunteers. We especially require the involvement of the "next generation". We need the young adults to tell us their concerns.

All of your perspectives are unique and valuable. If you are interested in attending a planning meeting, you can reach us through the web site. Learn with us as we try to enrich the lives of every individual in our community.

Coy White, President, FAMOHIO, Inc.

**FAMOHIO, INC. FOUNDING
FATHERS, BOARD AND PLANNING
COMMITTEE**

Six men founded FAMOHIO, Inc. in the spring of 1992. That year, "FAMOHIO" was the acronym for "First Annual meeting of Hemophiliacs in Ohio" but it has since meant "Family Annual Meeting of Hemophiliacs in Ohio."

FAMOHIO, Inc. was grown out of the frustration of these adult men and their colleagues who had been infected by HIV in part because of the failure of government, product manufacturers, hemophilia organizations and others to adequately manage the quality of factor and communicate in a timely manner the risks of treatment. These men believed that an annual meeting of hemophiliacs and their families would provide an opportunity to share information, educate themselves, and work together for their common good. It was hoped that such a symposium would minimize the likelihood of a recurrence of such a calamity.

Of the six men who organized FAMOHIO, Inc., Tommy Burr, Tom Drake, Ira Gaffin and Darrell Hairston have died. All four were active in and strong advocates of the hemophiliac community, and left behind loved ones as well as many friends who have ensured the continuation of FAMOHIO, Inc.

***A VERY SPECIAL THANKS TO THE
FAMOHIO PLANNING COMMITTEE
FOR ALL OF THEIR HARD WORK TO
MAKE THIS YEAR'S EVENT SO
SUCCESSFUL!!***

GENERAL INFORMATION, CONT.

will be provided by volunteers working with professional child care staff. A wide variety of activities will be provided during the day. Please refer to the "FAMOHIO kids" booklet. This year the children will remain in the program and be served lunch. Menu information was given on registration form. Katie Stentz coordinates the Children's Program.

YOUTH PROGRAM

The Youth Program on Saturday, August 4th is for children 7 years through 12 years old. The program will be provided at the Columbus Crowne Plaza North Hotel. The program begins at 9:30 a.m. with parent and child sign in. The Youth Program Coordinators, Hemophilia Treatment Center Nurse Charmaine Biega and Liz Miler and volunteers will provide educational and recreational programming for the children. The children will remain in the program and will be served lunch. If at any time on Saturday a child becomes ill, his/her behavior becomes unruly, the program staff will notify the parent and it will be their responsibility to assume responsibility. The youth will be participating in a structured aquatic program Saturday morning beginning immediately after registration and they are asked to come to the program with bathing suits on.

TEEN PROGRAM

Adolescent program for teens 13-17 will feature The Cruise Nest and other activities with adolescent child life specialists, peer counselors, and psychosocial professionals in Room 225. The program strives to promote the development of supportive relationships among peers within the bleeding disorders community. Teens have a chance to learn to "Do the Five," win raffle tickets and enter a drawing. The Cruise Nest is a room for teens to hangout with their peers, listen to music, socialize and have fun. This year the teen program will include lunch and a structured aquatic program Saturday afternoon in the hotel pool for the teens, please dress accordingly. If you have any questions regarding the Teen Program at FAMOHIO, please contact the Teen Program Coordinator Michele Robben.

GENERAL INFORMATION, CONT.

Exhibits

Visit FAMOHIO's exhibit area in the hotel foyer areas to speak with product manufacturers, service and nonprofit organizations.

Hotel Pools

The hotel pools with lifeguards present will be open for FAMOHIO attendees: Saturday, August 4th from 9:00 a.m. to 4:30 p.m. the pools will be reserved for a structured aquatic program, for the Teen and Youth program participants only. 9:00 p.m. to 11:00 p.m. open pools for all attendees.

Fitness Room

The fitness room will be closed for the duration of the FAMOHIO event.

Social Events

Carnival in Columbus! On Friday, join FAMOHIO in the Main Ballroom as we welcome Ventriloquist Denny Baker at 4:30, 6:30 and 8:30 p.m. for the kids as well as a 'resource room' of GREAT information and socializing for the adults! On Saturday, watch as the pavilion is transformed into a fun-filled Family Carnival: 12 games, bingo and card tables will be offered, with tons of free prizes and giveaways available!

CHILDREN'S PROGRAMMING

INFANTS' PROGRAM

The Infant's Program for children 3 to 24 months will be provided in the Columbus Crowne Plaza North Hotel Suites 325 and 340. Monica Snider, Occupational Therapist at the Nisonger Early Childhood Education Program and long time FAMOHIO Board member will coordinate the child care staff of child life volunteers and child care specialists from Cincinnati Children's Hospital. The Infants Program begins on Saturday, August 4th at 9:30 a.m. and close at 4:30 p.m. Parents will be responsible for the care and feeding of their children during 11:45 to 1:30 p.m. Check with registration for morning only drop-off times to make the transition easier for the babies and toddlers.

CHILDREN'S PROGRAM

The Children's Program for children 2 years through 6 years old will be provided in the Columbus Crowne Plaza North Hotel. The Children's Program begins Saturday, August 4th at 9:30 a.m. and closes at 4:30 p.m. Care

FACULTY

Carrie Baker has served as the advocacy manager for the Ohio Bleeding Disorders Council since January of 2006. In her role she monitors the Ohio legislative activity and other issues important to the bleeding disorder community, as well as facilitates statewide advocacy training programs for the OBDC. Carrie has a Bachelors Degree in Political Science from the Ohio State University.

Charmaine Biega, R.N. has been the hemophilia nurse coordinator at Columbus Children's since 1996. Previously, she worked with at Children's on the hematology/oncology unit at Children's.

Marjorie Gaffin, LISW, BCD is a Clinical Social Worker at the Columbus Children's Hospital Behavioral Health Center and is also in private practice where I see adults. Marge specializes in the anxiety disorders. Marge's husband, Ira Gaffin, was a hemophiliac, a founding member of FAMOHIO, and its first president. Marjorie also serves on the FAMOHIO Board of Directors.

Karen Gillespie, R.N. currently works for the University of Cincinnati Hemophilia Treatment Center. She is a graduate of the Jewish Hospital School of nursing and has over 30 years of nursing experience. She has worked the past 20 years in Hematology/Oncology and is learning the Hemophilia end, having worked now for a year at the University of Cincinnati. This is her first FAMOHIO meeting, and hopefully won't be her last.

Jill Harris P.T., M.A., has been a physical therapist for 34 years working at Children's Hospital Medical Center of Akron, with Bleeding Disorders. She has worked with children and adults with Bleeding Disorders through Children's Hospital's Bleeding Disorders Clinic, hospital inpatients, outpatient services, Amish Health Fairs as well as in their home. She served as a member of the Hemophilia Advisory Board for 15 years and is presently on the Bleeding Disorders Council. She has given presentations and written on different aspects of Physical Therapy in Bleeding Disorders for parents and professionals at the state and national level.

Sandy Hibner, R.N., BSN is a graduate of St. Elizabeth School of Nursing and Indiana Wesleyan University. She has over 30 years of nursing experience and has worked in hematology, oncology, critical care, surgery and research. She has worked as Hemophilia Resource Nurse at the West Central Ohio Hemophilia Treatment Center at Dayton Children's since 1997.

FACULTY, CONT.

Jeffrey D. Hord, M.D. received his Undergraduate and medical school training at the University of Kentucky Pediatric Training at Columbus Children's Pediatric Hematology Fellowship at Vanderbilt University in Nashville Upon completion of fellowship was on the faculty at Children's Hospital of Pittsburgh for 4 years. He is Professor of Pediatrics at the Northeastern Ohio Universities College of Medicine Has published articles and book chapters about a variety of Pediatric Hematology/Oncology topics Serves on the BCMH Hemophilia Advisory Subcommittee and represented Ohio Children's Hospital Association on the recent Ohio Legislative Study Committee on Future Funding of BCMH.

Pamela Kibbe, RN, MS, CNP is a Hepatology RN, NP/OSU currently serves as a Hepatology Nurse Practitioner at the Ohio State University Medical Center.

Kathy Kirkpatrick is the education coordinator for the Hematology/Oncology division at Children's Hospital in Columbus. She previously served a variety of chronically ill populations at the hospital as a clinical social worker.

Justin Lindhorst was diagnosed with severe Hemophilia A at birth. As a child Justin narrowly missed contracting HIV and battled an inhibitor. Reaching his teen years Justin was diagnosed with Hepatitis C, which he was luckily enough to clear without any treatment. A recent graduate from the University of Cincinnati, Justin holds degrees in both German and Organizational Communications.

Claudia Lupia, R.N. B.S. is the hemophilia nurse coordinator at Columbus Children's Hospital. She earned her Bachelors Degree in Special Education and an associate degree in nursing while earning her bachelor's degree. She has a variety of nursing experience, but has spent most of her nursing career in hematology/oncology.

Cathy M. Tiggs MSSA, LSW works for University Hospitals Case Medical Center in Cleveland, Ohio and is the Adult and Pediatric Social Worker at their Hemophilia Treatment Center. Cathy is a licensed Social Worker and holds a Masters Degree in Social Science Administration from Case Western Reserve University. Prior to her work at the treatment center, Cathy held a Senior Management position at the Cuyahoga County Department of Children & Family Services.

Pam Williams is the mother of two sons, ages 20 & 15, both with mild Hemophilia B. The boys were diagnosed 10 years ago, following Joshua's ear reconstructive surgery. The oldest, Joshua, is a senior at Capital University and he self-infuses. Thomas, is a sophomore at Western Brown High School. Pam has a BA in Sociology and a MEd in Educational School Counseling. She is employed at Shriners Hospital for Burns/Cincinnati in the Out Patient Clinic.

GENERAL INFORMATION

Registration

All attendees MUST be registered by Saturday, August 4th by 8:30 a.m. a.m. in order to participate in all FAMOHIO activities Saturday morning, afternoon and evening and Sunday morning. The registration area is located in the Capital Room, see below for hours. All attendees must also register with the hotel registration.

Registration Hours

Friday August 3rd 3:00 p.m. to 8:30 p.m.

Emergency Care

FAMOHIO directs all medical emergencies to the front desk for assistance.

Wheelchair Accessibility

The hotel is wheelchair accessible. FAMOHIO has made all wheelchair accessible sleeping rooms available on a first come, first serve basis. If you require a special room or have any other special needs, please speak with the hotel staff directly. There are wheelchairs available during the FAMOHIO weekend.

No Smoking

FAMOHIO adheres to the hotel's strict no smoking policy.

Treatment Suite/Sharps Disposal

FAMOHIO will not provide a treatment suite or sharps container during the weekend.

Children's Programming

See Children's Programming section for detailed information.

Infants 3 months to 23 months

Children's 2 yrs to 6 years

Youth 7 years to 12 years

Teen 13 years to 17 years

Meeting Rooms

All FAMOHIO meeting sessions will be held at the Columbus Crowne Plaza North Hotel. Each room's activities for August 5th and 6th will be noted in this program and by information boards outside of each room.