

20 AUGUST 17

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## HIT IT OUT OF THE PARK

As the president of FAMOHIO and a baseball enthusiastic, I am doubly happy to welcome you to FAMOHIO 2017! We are going to "hit it out of the park" this weekend and score big! The "team" of our founding fathers created FAMOHIO to educate and ensure positive outcomes for all affected with bleeding disorders. The original team's mission was boundless yet in size the first meeting was like a Pee Wee game. Over the years, we have moved forward, grown in size and purpose and I can now say "we are winning the World Series!"

So, with this positive momentum in place, I challenge each and every one of you to think about and decide what your "it" is. Your "it" you might ask? What is he saying? Let me explain. "Hit it out of the ball park" is our theme. Decide what "it" you are going to "hit out of the park." Will "it" be learning more about genetics or advocacy? Will "it" be a commitment to listen more carefully to the presenters and vow to take their message home and incorporate change in your day to day living? Will "it" be welcoming new friends and connecting with old friends to further the bond between blood brothers and sisters?

Last year we introduced the "Celebration Room." Stop by and enjoy the many accomplishments and former and current participants of FAMOHIO shown through pictures and media. FAMOHIO has had a great run (home run that is)!

I wish to thank the generous vendors for their financial and educational support. Promise me you all will stop by and personally thank them and discuss their products and services. Keep in mind, FAMOHIO would not happen without financial assistance.

I would be remiss if I did not thank the hotel staff who works extremely hard to meet our needs. Many staff members work extra hours just to make our stay as pleasant as possible. Please be on your best behavior during our stay at the Northwest Marriott and give a nod of thanks to the staff.

In addition, I would like to thank the board and planning committee of FAMOHIO. It is impossible to tally the number of hours donated by these two committees to plan and execute this weekend. The board and planning teams are committed to each and every one who attends FAMOHIO.

Let's "hit it out of the park!" Go team go! Did I mention the Toledo Mud Hens?



Sincerely,

Josh Crossgrove President, FAMOHIO crossgrovekj@gmail.com 419.796.9166

## **FAMOHIO AWARDS**

Of the six men who organized FAMOHIO, Inc., Tommy Burr, Tom Drake, Ira Gaffin, and Darrell Hairston have died. All four were active and strong

advocates of the bleeding disorder community. They left behind loved ones as well as many friends who have ensured the continuation of FAMOHIO. Inc. To honor the founders and current advocates. a series of awards have been created. Please read the description of the awards on ou rwebsite and consider nominating a deserving recipient.

Award nominations are accepted throughout the year. Instructions are listed on the website.



Jermaine Davis receiving the Thomas H. Burr Advocacy Award in 2016

Over the weekend, members of the FAMOHIO board will announce the award recipients for 2017. The FAMOHIO board sends sincere congratulations and appreciation to this years' most worthy winners.

The highest award given by FAMOHIO, Inc. is the IRA GAFFIN MEMORIAL AWARD. This award is presented to an individual who has provided extraordinary voluntary service to the hemophilia community. This merit based award is offered once each year and is open to any individual or couple whose unstinting service on behalf of the hemophilia community of Ohio exemplifies the generous spirit of Ira Gaffin. The following names are the awardees who have achieved this great honor.



Cindy Michael (2016 Ira Gaffin Recipient), Josh Crossgrove, and Marge Gaffin

2016: Cindy Michael 2015: Glenn Pierce, M.D., Ph.D. 2014: Karen Gillespie 2013: Les and Gloria Gutter 2006: Randy Clites 2012: (none awarded) 2011: Teresa Bridges Rutter, Madeline Heffner, & Nancy Duffy

2010: Elizabeth Billow 2009: Dena Shepard 2008: (none awarded) 2007: Polly Partin-Welch 2005: Linda Wacha 2004: Ruth Savlor **2003:** Sylvia Jordan

2001: Jim Sites 2000: Bill Dennis 1999: Rick Sites

1998: Michael Para. M.D. 1997: Ralph Gruppo, M.D. 1996: Dirk Scheerhorn, Ph.D. 1995: Paul and Rosie Haas 1994: Tom & Monica Burr

2002: Joseph Palascek, M.D.

## AGENDA 2017

## FRIDAY, AUGUST 4th

3:00 PM REGISTRATION OPENS

Hotel Lobby

3:00 PM NEW FAMILY WELCOME

Hallway - near restaurant

3:00 PM - 9:00 PM PLATINUM & GOLD VENDOR DISPLAYS

Atrium

4:00 PM - 6:00 PM CELEBRATION ROOM OPEN

Westerville

4:30 PM - 5:30 PM 7-12 CHILD CARE REGISTRATION OPENS

Hallway - by elevators

6:00 PM - 7:30 PM DINNER - Sponsored by Shire

Ballroom

7:30 PM - 10:00 PM POOL OPEN

7:30 PM - 10:00 PM WOMEN'S COMFORT ROOM

Franklin Meeting Room

7:30 PM FAMOHIO FITNESS WALK

Hotel Entrance

7:30 PM ICE CREAM TRUCK

Hotel Entrance

9:00 PM - 11:00 PM EDUCATIONAL SUITE - Sponsored by Shire

Dublin - I, II, III

8:00 PM - MIDNIGHT TEEN SUITE OPEN

Rooms 119-121

8:30 - 10:00 PM CELEBRATION ROOM OPEN

Westerville

## AGENDA 2017

## SATURDAY, AUGUST 5th

7:00 AM - 8:30 AM BREAKFAST - Sponsored by Cascade

- vendor displays open

Ballroom

8:30 AM - 9:00 AM CHILDCARE REGISTRATION OPENS

See page 16 & 17 for locations

9:00 AM - 11:45 AM YOUNG ADULTS

- Will join lunch and Ask the Doc

Powell

9:00 AM - 10:00 AM MORNING SESSION 1

Aging in Hemophilia, Bioverativ

Dublin I

Women's Issues/Carriers, Dr. Dunn

Dublin II

Insurance/CMH/Medicaid, Randi Clites

Dublin III

Basics of Bleeding Disorders, Laura Jean Siggins, MSN, RN

Dublin IV

10:30 AM - 11:30 AM MORNING SESSION 2

Physical Therapy, Scott Daniels

Dublin I

VWD, Laura Jean Siggins, MSN, RN

Dublin II

Hemophilia is a Genetic Condition,

Trish Underland, PNP

Dublin III

## **AGENDA 2017**

11:30 AM INFANTS MUST BE PICKED UP

11:45 AM - 1:00 PM LUNCH & AWARDS

Ballroom

1:15 PM INFANTS RETURNED TO CHILDCARE

1:30 PM - 2:30 PM PLENARY SESSION - ASK THE DOC

Ballroom

2:30 PM CHILDCARE CLOSES

3:00 - 4:30 PM CELEBRATION ROOM OPEN

Westerville

5:00 PM LEAVE FOR COLUMBUS CLIPPERS GAME

SUNDAY, AUGUST 6th

9:00 AM - 11:00 AM BREAKFAST & WRAP-UP

WITH ELEC SIMON

Ballroom

## LES GUTTER MEMORIAL SCHOLARSHIP



2015 & 2016 scholarship winner, Jenna Hoffman performing at the 2016 FAMOHIO plenary session

In 2013, the Les Gutter Memorial Scholarship was created in memory of Les Gutter, who was the dedicated treasurer of FAMOHIO for more than twenty-years. Les's financial expertise, attention to detail, and strong dedication helped ensure the continued success of FAMOHIO, Inc.

Recently the board of FAMOHIO committed to awarding one \$2,000.00 scholarship yearly, but has the authorization to increase the number of awards based on the qualifications

of the applicants. In 2016, the scholarship committee awarded three \$1,000.00 scholarships:

Jenna Hoffman – University of Mount Union Lee Huntsberger – Wright State University Steven Miller – Youngstown State University

All attendees of FAMOHIO who have a bleeding disorder and are seeking post high school education are eligible to apply for a Les Gutter Memorial Scholarship. Forms and instructions are located on our website. http://famohio.org/scholarship/

Remember to purchase 50/50 raffle tickets. The profits are applied to the scholarship account.

## SATURDAY, AUGUST 5TH

Morning Session One: Multiple Options

9:00am-10:00am

## Aging in Hemophilia – sponsored by Bioverativ

By Carol DeMatteis Dublin I

This CoRe conversation will explore the topic of aging with hemophilia. It will incorporate suggestions from older members of the community that future generations might find helpful.

Carol DeMatteis is a Community Relations & Education Manager at Bioverativ. Carol has a lifetime of personal experience with bleeding disorders plus over a decade of professional experience at an HTC.

Her father had severe hemophilia and she considers herself a survivor of the community's AIDS crisis. She is a mother of three, including a teenage son with severe hemophilia as well as a young adult daughter with vWD. Because of Carol's personal and professional advocacy experience she is aware of the complexities we experience living with bleeding disorders.

She enjoys connecting by listening to stories of our unique journey through life with a bleeding disorder. Carol resides in northeast Ohio with her husband, 3 kids, and cat "Sugar".

## Diagnosis and Management of Bleeding Disorders in Women and Girls

By Amy Dunn, MD Dublin II

- We will discuss the different types of bleeding disorders seen in women and girls
- We will discuss signs and symptoms of bleeding disorders
- We will discuss treatment options
- We will discuss research opportunities

This session will be relevant to all affected females and family members of affected females, including carriers.

Dr. Dunn received her medical degree from Wright State University School of Medicine in Dayton, Ohio and completed her pediatric and pediatric hematology/oncology training at Emory University in Atlanta, Georgia. She is an Associate Clinical Professor of Pediatrics at Nationwide Children's Hospital/Ohio State University where she is the director of pediatric hematology at the hemophilia treatment center.

Dr. Dunn is a member of various professional associations including the American Society of Hematology, World Federation of Hemophilia, International Society of Thrombosis and Hemostasis, International Pediatric Hemophilia Network, International Prophylaxis Study Group, and the Hemophilia Research Society.

Dr. Dunn has served as a reviewer for hematologic journals including the Journal of Pediatric Blood and Cancer, the Journal of Thrombosis and Hemostasis, Blood and Hemophilia. She has published numerous peer-reviewed articles, abstracts, and textbook chapters. In addition, she has presented at national and international medical symposia. She has received awards that include US News and World Report Top Doctors and the Atlanta Business Chronicle healthcare Hero for Healthcare Innovation.

## Updates in the Current Health Care Landscape and What You as a Patient Advocate Can Do

By Randi Clites Dublin III

Randi will provide updates regarding the current health care landscape and will inspire you to get more involved in advocating for yourself and the entire bleeding disorders community. Everyone within the community advocates on some level, and this presentation will provide an overview of exactly how much you already do and how you can step it up just a bit to help protect access to quality care moving forward. Randi will also share information about the new parent/patient advocacy role/program recently introduced by the Ohio Bleeding Disorders Council (OBDC). Randi Clites is the Program/Advocacy Manager at the Northern Ohio Hemophilia Foundation and Advocacy Coordinator for the OBDC. She has served for 13 years on the Parent Advisory Council (PAC) and eight years

as a member of the Ethics committee at Akron Children's Hospital. In addition, Randi is an 11 year member of the PAC for the Department of Health for the Children with Medical Handicaps Program, and currently VP of Board of Directors for Cascade Hemophilia Consortium.

Randi graduated from Hiram College with a Bachelor degree in Business Management and a minor in Political Science. She is an Association of Maternal and Child Health Program Family Scholar graduate.

Randi lives in Ravenna, Ohio with her husband, Matt, and her son, Colton. Colton is now 15-years old. He was born with severe hemophilia (no family history) and is a leukemia and brain bleed survivor.

# By Laura-Jean Siggins, MSN, RN Dublin IV

What does this mean "bleeding disorder?" Is it contagious? Can one lead a normal life? Do I need to bubble wrap my child? Can I let them play like other kids? Will I always feel scared? Can I leave them with a sitter? Can I let them go to school unattended? What do I do in an emergency? Oh my! Now I have a diagnosis, but what does all this mean? Let us help you understand what to do and where to go from here. You can do this!

Laura-Jean has been a pediatric nurse in hematology for over 27 years. She graduated with a Bachelor of Science of Nursing degree from the University of Michigan, School of Nursing in 1995. She furthered her education by obtaining a Master's Degree in Nursing from the University of Phoenix. For the last 15 years Laura-Jean has enjoyed working at the Hemophilia Treatment Center in Ann Arbor.

Laura-Jean describes her nursing passion as "I love to teach patients, families, and staff." She particularly likes helping families and patients conquer the fear of accessing their child's or their own ports and doing infusions. She incorporates therapeutic and distraction therapies to assist with difficult infusions and is qualified to teach these beneficial techniques to others.

Laura-Jean is active with the local hemophilia foundation working with the girls' clinic and women's group. She works tirelessly each year at Camp Bold Eagle. Laura-Jean has presented locally, regionally, and on a national level.

## SATURDAY, AUGUST 5TH

Morning Session Two: Multiple Options 10:30am-11:30am

# How to Manage Joint Pain Associated with Hemophilia By Scott Daniels PT, DPT Dublin I

Joint pain is common in those with bleeding disorders. In this session, you will hear helpful tips for managing joint pain associated with osteoarthritis due to joint bleed. You will also be provided with strategies to reduce joint stress and improve joint health with day to day activity. There will be time left for a question and answer session for issues related to joint pain and joint health.

Scott is a 1994 graduate of the physical therapy program of West Virginia University. He received his Doctorate of Physical Therapy from the Evidence in Motion Institute of Health Professions in 2016. He has over 20 years of experience in orthopaedic and sports physical therapy settings.

He is currently a Manager of Rehabilitation Services for Mercy Health, Orthopaedics and Sports Rehabilitation in Cincinnati, OH. Scott has had extensive continuing education and speaking opportunities with emphasis in shoulder, knee and spine evaluation and treatment. Scott's course material has been described as appropriate for being used to treat individuals with knee, shoulder and spine dysfunction across the life-span and is geared toward therapists in a wide variety of settings including outpatient, sub-acute and long-term care facilities. Scott lives in Lawrenceburg, Indiana, with his wife of 20 years, Jennifer, a 15-year-old son, Gavin, a 13-year-old daughter, Avery, and 12-year-old son Max. His son, Max, has mild hemophilia A. Based on what he has learned about his son's condition; Scott is committed to using his expertise to help those with bleeding disorders.

#### Von Willebrand Disease

By Laura-Jean Siggins, MSN, RN, CPN, CPST Dublin II

Wow, disease? Von Willebrand Disease sounds so ominous! What does this mean? What should I do? Should I keep my child at home? Should I call in the troops? Ride a bike, pad the bed, so many questions are running through my head. Help! What is a platelet and what does it mean to be dysfunctional?

Come and let us help you understand all this strange terminology. We will break down the words so they make sense.

See bio under Basics of Bleeding Disorders.

# Hemophilia is a Genetic Disorder – sponsored by Shire By Trish Underland, PNP Dublin III

Hemophilia is usually passed down through families. In this program, you'll learn how genetics influences the chances of inheriting hemophilia or having a child with this disorder.

Trish earned her undergraduate nursing degree at the University of Virginia and Master of Science degree from the University of Maryland and is a board certified Pediatric Nurse practitioner. Trish has over 30 years of hospital based nursing experience at Johns Hopkins Hospital in Baltimore MD. She has worked in a variety of settings that included inpatient pediatrics, pediatric emergency room and as the nurse coordinator for the Hemophilia Treatment Center (HTC).

While at the HTC (for 14 years), Trish enjoyed working with families where multigenerational family members could be affected with the same bleeding disorder. She found that the family dynamics in these situations could often be challenging but more often than not the understanding between family members provided a support system that was not only unique but truly inspiring.

Trish is passionate about patient education. She has found that helping patients understand and manage chronic illnesses, particularly in the setting of a new diagnosis, is one of the most rewarding aspects of the nursing role. Currently, Trish a senior clinical specialist with Shire.

## SATURDAY, AUGUST 5TH Afternoon Session: Plenary 1:30pm-2:30pm Ballroom

# Ask the Doc (back by popular demand!) By Dr. Ralph Gruppo

Come to this innovative session to ask questions and discuss future trends in the treatment of bleeding disorders with leading hematologist, Dr. Ralph Gruppo. The session will be interactive and conducted in a relaxed format. Questions can be asked verbally or anonymously written on cards. Don't miss this exciting opportunity to "ask the doc."

Dr. Gruppo is the director of the Hemostasis and Thrombosis Program within the Division of Hematology, and former director of the Special Hemostasis and Research Laboratories at Cincinnati Children's Hospital Medical Center. He is also program director for the National Hemophilia Foundation's Clinical Fellowship Training Program.

Dr. Gruppo has published over 70 peer-reviewed manuscripts, invited reviews, and textbook chapters. He has served on the board of directors for numerous hemophilia advisory committees. Dr. Gruppo's research interests are hemophilia, particularly prophylaxis and immune tolerance of inhibitors, and on the etiology, diagnosis and treatment of thrombotic diseases in children.

## **ADDITIONAL SPEAKERS**

#### MATT OLOVICH

Matt Olovich is a recent graduate of Guerin Catholic high school in Noblesville, Indiana. Matt graduated with academic honors and as an Honor Society member. Matt was a 4-year starter and letterman for Guerin High School in baseball and set school records for the most hits, doubles and triples in his career. Matt was voted by opposing coaches as First Team All Conference and was named an



Academic All-State baseball player. Matt will continue his baseball career at Franklin College in Indiana where he will study biology and physical therapy.

Matt is a severe Hemophilia A patient and has used prophylaxis all his life. Rather than be upset about the things you cannot do because of hemophilia, Matt believes it is better to focus on what you can do and make the most of those opportunities.

## **ELEC SIMON**

Elec Simon was born with rhythm in his soul. Every object was an instrument waiting to be played. Every instrument had a song waiting to be heard. Elec was the conductor of his surroundings.

After graduating from high school, Elec took his thirst for music to New York. He wasn't interested in joining the ranks of students in schools like Juilliard, or the Berklee College of



Music; he wanted to explore music from the ground up, to discover the roots that moved him as a child.

## **ADDITIONAL SPEAKERS**

There, on the streets and subway platforms of New York City he began to find the rhythm that would define his life. He would busk alongside many of the great street performers of our generation such as Larry Wright and William Johnson. Those moments were the springboard for what was to come – a starring role in the touring production of STOMP. Elec spent over a decade with STOMP, touring across the country, experiencing life as a stage performer in one of the world's best received shows, but even that experience wasn't enough to feed his hunger for music.

After his time with STOMP, Elec decided to return back to his home in Canton, Ohio where he felt the need to give back to his community. Dear to his heart was the subject of anti-bullying. As a child, Elec had lost a friend to bullying. He realized he could use his music to make a change and began performing in schools where his mix of from-the-streets wisdom and stage experience allowed him to connect with the children in front of him.

He doesn't just stand there and lecture them – he puts the music directly in their hands. Every Elec Simon assembly includes a full band, a huge line of buckets for the kids to play along with, and Elec's positive, high-energy message about tolerance, love and understanding.

If Elec looks familiar to you, that's for good reason. Not only has he been featured on the stage with STOMP and major news outlets who cover his message, he can also be seen playing with the Cleveland Cavalier's Q-Stix, who play every Cav's home game. They were also invited to play during the NBA 2016 All-Star weekend in Toronto, Canada.

Elec Simon has made it his life's mission to spread his brand of music. It's a rhythm based off of nature's oldest drum; the heart, and it's from the heart that his message flows – teach our children to love one another and the world will grow up with them to be a better place.

# Wolmens Confort Room

FRIDAY, AUGUST 4TH 7:30pm to 10:00pm Franklin Meeting Room

Grab a refreshment (coffee, tea, water, lemonade) and a treat, enjoy a craft project, gab with the girls, take a break from the kids, relax and have some fun!

Sponsored by Northwest Ohio
Hemophilia Center at The Toledo
Children's Hospital and the Northwest
Ohio Hemophilia Foundation

Must be 18 to enter

## **WEEKEND PROGRAMS**

#### **INFANT'S PROGRAM**

The Infant's Program for children 3-35 months will be provided in First Floor Suite and Connector 120 & 122. Monica Snider, an occupational therapist at the Nisonger Early Childhood Education Program and long-time FAMOHIO, Inc. board member coordinates the childcare staff of child life volunteers and child care specialists from Cincinnati Children's Hospital. The program begins on Saturday, August 5th at 8:30 am and closes at 11:30 am. Parents will be responsible for the care and feeding of their children during lunch in the Ballroom. Children can be returned to daycare at 1:15 pm. Children are to be picked up at 2:30 pm.

#### CHILDREN'S PROGRAM

The Children's Program for children 3 to 6 years will be provided in Arlington/Grandview/ Muirfield rooms. The program begins Saturday, August 5th at 8:30 am and ends at 2:30 pm. Parents should sign their children "in" beginning at 8:30 am at the table located in the hallway in front of the assigned rooms. Children need to be picked up at 2:30 pm. Care will be provided by volunteers working with professional child care staff. A wide variety of activities will be provided during the day. The children will remain in the program and be served lunch. Jennifer Klingbeil coordinates this program.

#### YOUTH PROGRAM

The Youth Program is designed for children 7 to 12 years of age. The program will take place in Dublin V and Dublin VI. The program begins at 8:30 AM with check-in and concludes at 2:30 pm. Avoid the check-in line on Saturday morning by checking "in" your child on Friday night between 4:30 and 5:30 PM outside the Columbus/Franklin room.

The youth program coordinators are hemophilia nurse coordinator, Charmaine Biega, and hemophilia social worker, Linda Casto. Both Charmaine and Linda work at Nationwide Children's. They, along with additional volunteers, will provide educational and recreational programming for the youth. Two exciting presenters are scheduled for this year. Bleeding disorder education will be taught by Mike Rosenthal, sponsored by Bayer, using interactive and fun teaching activities. And, motivational messages will be presented by Elec Simon. The attendees will have a chance to swim in the hotel pool. Please have participants wear or bring swimsuits. Towels will be provided. Attendees will also

## **WEEKEND PROGRAMS**

be served a pizza lunch. If, at any time, a child becomes ill or his/her behavior becomes unruly, the program staff will notify the parents and they must assume responsibility.

## **TEEN PROGRAM**

The Teen Program is for participants ages 13-17. Michele, Larry, and Matt Robben have been in charge of the Teen Program for over a decade. Matt had to miss this year's event, but Michele and Larry's adult son, Nick, has agreed to "pitch" in. Michele and Larry have degrees in education and have extensive experience teaching children of all ages. The program will take place in 119-121 Boardroom. The program will again feature the popular Saturday night raffle. Increase your odds of winning by collecting raffle tickets given at the following sessions: Presentations by Matt Olovich and Elec Simon. Don't miss out! Check the flyer for further details. These presentations will be held during the day on Saturday in the teen room.

#### **TEEN PROGRAM HOURS:**

Friday, 8pm to midnight
Saturday, 9am-4pm and after the ballgame to midnight

#### YOUNG ADULT PROGRAM

Persons 18 years-old to 25 years-old are invited to gather in the Powell Executive Boardroom at 9:00 am. This program will headed by Marina Bishop, social worker from Cincinnati Children's Hospital Medical Center. Identifying and obtaining work that deals with your passion is the main theme. How to be interview ready will also be explored. The young adults will join the adults for lunch and the Ask the Doc session after lunch.

#### **CELEBRATION ROOM**

The celebration room commemorates 26 years of FAMOHIO with various pictures, videos, and memorabilia of past FAMOHIO events. A memory book will be available where folks can write their name or document thoughts. The celebration room will be set up in the Westerville Executive Boardroom. Drop by and celebrate the many accomplishments of FAMOHIO!

Open: Friday, 4:00-6:00pm & 8:30-10:00pm | Saturday, 3:00-4:30pm

# Platinum Level

#### **BIOVERATIV**

133 Boston Post Road Weston, MA 02493 585.737.9060 www.Bioverativ.com www.Eloctate.com

www.Alprolix.com



#### CASCADE HEMOPHILIA CONSORTIUM

[Provider of Hemophilia/HIV/Hepatitis Medications & Services]
517 West William Street CANN Arbor, MI 48103 H
800.996.2575 & fax 734.996.5566

www.cascadehc.org Email: info@cascadehc.org



#### SHIRE

540 W Madison St. Chicago, IL 60661 617.349.0200 www.Shire.com



# gold level

#### **BAYER HEALTH CARE**

100 Bayer Boulevard Whippany, NJ 07981-0915 888.606.3780



#### **APTEVO**

400 Professional Dr, Suite 400 Gaithersburg, MD 20879 Tel: 240.631.3200 Fax: 240.631.3203 http://aptevotherapeutics.com



## silver level

#### NATIONWIDE CHILDREN'S HOMECARE

[IV Homecare Services, Skilled Nursing] 700 Children's Dr Columbus, OH 43205 614.355.1162

## bronze level

#### **ACCREDO**

[Specialty Pharmacy for all bleeding disorder products] 201 Great Circle Road Nashville, TN 37228 866.851.0153

#### AKRON CHILDREN'S 340 B FACTOR PROGRAM

Akron Children's Hospital One Perkins Square Akron, OH 44308 330,543,3513

#### **ALNYLAM PHARMACEUTICALS CAMBRIDGE**

300 Third Street 3rd Floor Cambridge, MA 02142

Tel: 617.551.8200 Fax: 617.551.8101

### **CINCINNATI CHILDREN'S HOMECARE PHARMACY**

[Infusion, pharmacy and factor products] 3333 Burnet Ave Cincinnati, OH 45229 MLC 5017 513.636.4663

## **COTTRILLS PHARMACY**

[Homecare] 4919 Ellicott Rd Orchard Park, NY 14127 716.508.8481

#### **CSL BEHRING**

1020 First Ave King of Prussia, PA 19406 610.878.6000

## CVS/CAREMARK

[Full array of blood clotting factors and ancillary supplies] 800 Bierman Ct Mount Prospect, IL 60056 866.792.2731

#### **GENENTECH**

S. San Francisco, CA 1.800.551.2231

#### **GRIFOLS**

79 T.W. Alexander Dr 4101 Research Commons Research Triangle Park, NC 27709 814.483.9588

#### **PFIZER HEMOPHILIA**

235 E. 42nd Street New York, NY 10017 1.800.710.1379

## **MATRIX HEALTH GROUP**

[Healthcare Management providing Comprehensive Pharmacy Education, and Support to the bleeding disorders community] 3300 Corporate Ave Suite 104 Weston, FL 33331 877.337.3002

## **NOVO NORDISK, INC**

[Changing Possibilities in Hemophilia] 800 Scudders Mill Rd Plainsboro, NJ 08536 609.987.5800

#### **OCTAPHARMA**

10644 Westlake Dr. Charlotte, NC 28273 Tel: 704.654.4600 Fax: 704.654.4700

#### **RARE PATIENT VOICE**

https://rarepatientvoice.com/



DAYTON CHILDREN'S FACTOR PROGRAM

OHIO STATE HEMOPHILIA FACTOR PROGRAM

## THANK YOU!

## **BOARD MEMBERS**

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Josh Crossgrove

# VP Planning & Scholarship Committee

Sandy Hibner

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## VP Legal

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Teresa Rutter

#### Secretary

Krista Crossgrove

## **Event Coordinator**

Lisa Raterman

## <u>Les Memorial</u> Scholarship Committee

Marge Gaffin

Elizabeth Miller

Gloria Gutter



## **TRUSTEES**

Tina Ascough

Charmaine Biega

Linda Casto

Elizabeth Miller

Dwanna Rutter

Monica Snider

**The Planning Committee** is comprised of many members of the board and in addition, Marina Bishcoff, Allison French, Selina Jackson, Diane Linker, Jaycee McCain, and Rania Salem.

## GENERAL INFORMATION

## **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 staff directly. There are wheelchairs available during the FAMOHIO weekend.

#### NO SMOKING

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

## TREATMENT SUITES/SHARPS DISPOSAL

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

## **EXHIBITS/VENDORS**

Visit FAMOHIO's exhibit area in the hotel atrium areas to speak with product manufacturers, service, and non-profit organization representatives. See the Schedule of Events for available times.

# HOTEL MAP

