

2019 Conference August 2nd - 4th



FAMOHIO AWARDS	2
LES GUTTER MEMORIAL SCHOLARSHIP	6
BOMBARDIER BLOOD	11
WEEKEND PROGRAMS	13-14
ZOO TRIP/GROUP PHOTO INFORMATION	19
GENERAL INFORMATION & HOTEL MAP	21-22

It is with great honor as the President of HIO, I welcome you all to the 2019 See Us Soar Hear Us Roar Program.

I want to begin by taking this opportunity to tell you a little bit about myself and the journey that led me here today. Fifteen years ago, my husband Greg, daughter Ali and I welcomed baby boy Lucas into our family. Not long after he was born, he was diagnosed with Hemophilia B. We had no idea what this meant or how it would affect our lives, but we were scared to death. My sister then also had her boys tested and we found out that my 8-year-old nephew also had Hemophilia B so as a family we began this journey together.

Not long after Lucas was born, I became involved with our local chapter. I volunteered for a fundraiser and met other mothers of boys like ours. We attended many events and eventually made it to our first FAMOHIO. It was amazing to meet all the families from across the state of Ohio who were a lot like us. The educational opportunities were endless and networking with families helped our family form life long friendships with people we most likely would have never met had circumstances been different.

Fast forward a few years to when my good friend and fellow hemo mom Pam talked me into volunteering at FAM and eventually becoming a board member. I participated in many FAMOHIO's until eventually the opportunity for me to become board President presented itself. I am a work in progress. Learning and growing every day with the help and support of an awesome board and community. I am very thankful for all the hard work and dedication the board has put forth in planning this weekend's event.

I encourage each one of you to attend the education sessions, network with one another, build the lifelong friendships that my family and I have, and most of all have fun. I promise you will not be disappointed.

Sincerely, Tina Asco'ugh President, FAMOHIO

The Board of FAMOHIO sends thanks to our generous vendors for their financial and educational support. Please make time to connect with each representative at their displays. FAMOHIO could not exist without financial assistance.

The staff at the Northwest Marriott have continuously provided exceptional service. Please be on your best behavior and take an opportunity to thank the dedicated staff.

The Board of FAMOHIO hopes you will make the most of the program provided. Many hours have been donated in preparation for the event. The board thanks Lisa Raterman and her staff for their expertise in planning and executing this grand event. Remember when we roar we are able to soar!

The six founding fathers of FAMOHIO were active and strong advocates of the bleeding disorder community. These brave men knew firsthand what having a bleeding disorder entailed in a time when treatment was very limited. In addition, they suffered through the tainted blood/factor tragedy. However, rather than wallowing in self pity our founders came together and created an educational forum known then as First Annual Meeting of Hemophiliacs in Ohio and now known as Family Annual Meeting of Hemophiliacs in Ohio or FAMOHIO. These founders realized **EDUCATION is POWER!**

To honor our great founders and current advocates, a series of awards have been created and are awarded annually. On the FAMOHIO website the description of awards are listed. We wholeheartedly accept nominations and would love to review any nominations we receive. Please consider nominating someone who has helped you on your journey.

Over the weekend, members of the FAMOHIO board will announce the award recipients for 2019. The FAMOHIO board sends sincere congratulations and appreciation to this years' most worthy winners.

he highest award given by FAMOHIO. Inc. is the IRA GAFFIN MEMORIAL AWARD. This award is resented to an individual who has provided extraordinary voluntary service to the hemophilia ommunity. This merit based award is offered once each year and is open to individual or ouble whose unstituting service on behalf of the hemophilia community of Ohio exemplifies the enerous spirit of Ira Gaffin. The following names are the awardees who have achieved this great onor.



3:00 PM Registration Opens

Hotel Lobby

3:00-6:00 PM New Family Welcome

Hallway – near restaurant

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

Atrium

4:30-5:30 PM 7-12 Child Care Registration Opens

Hallway - by elevators

6:00-7:00 PM Dinner

- Sponsored by Takeda

Ballroom

7:30-10:00 PM Pool Open

7:30 PM FAMOHIO Fitness Walk

Hotel entrance

7:30 PM Ice Cream Truck

Hotel entrance

7:30- 8:45 PM Women's Comfort Room session one

- Sponsored by Northwest Ohio

Ballroom

8:45-10:00 PM Women's Comfort Room session two

- Sponsored by Northwest Ohio

Ballroom

8:30-11:00 PM Educational Night

- Sponsored by Takeda

Ballroom

8:00-midnight Teen Suite Open

Rooms 119-121



7:00-8:00 AM Breakfast – Sponsored by Cascade

Ballroom

8:00-8:30 AM MyBDC presentation Maria Santaella, MSN, NHF

7:00-8:45 AM Sponsor Displays

Atrium

8:00-8:45 AM Childcare registration

9:00 – 2:30 PM Youth Program

9:00-10:00 AM Morning Session 1

Exercise for Everyone - Debbie Shijo, PT

Dublin III

Medicare 101: Learn about your Medicare benefits and options - Becky Hayward

Dublin IV

Choose to take Control - Maria Santaella, MSN

Dublin V and VI

10:00 -10:30 AM Break – Sponsor time

10:45 -11:45 AM Morning Sessions 2

Medical Marijuana - Maria Santaella, MSN

Dublin III

New Products and the Future of Hemophilia

Treatment - Dr. Riten Kumar

Dublin IV

Sharing your Story: Advocacy in the Bleeding Disorder Community - Honey Blankenship

Dublin and VI

11:45 AM Pigent infants

11:45 -12:00 PM BREAK - Sponsor time

Infants must be picked up

12:00 - 1:15 PM Lunch/Awards

1:15 PM Infants return to childcare

1:30 –2:30 PM Plenary Session – 18 years and older to attend

Advocacy ambassadors

Ballroom

2:30 PM Child Care Closes

2:30 - 3:30 PM Sponsor time

3:45 PM LEAVE FOR THE ZOO

4:00 PM Zoo opens to our group

5:00 PM Dinner Buffet

7:30 PM Animal presentation/Dessert

SUNDAY, AUGUST 4th

9:00-10:30AM Breakfast and wrap-up

Ballroom

10:30AM Bombardier movie (optional)

Please note that all buffet lines will be open for one hour



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.

The board of FAMOHIO has committed to awarding one \$2,000.00 scholarship yearly, but also has the authorization to increase the number of awards based on the qualifications of the applicants. In 2018, the scholarship committee awarded two \$2,000.00 scholarships:



Steven Miller Youngstown State University



Olivia Hoff Saint Mary's College

Steven just completed his junior year and is pursuing a major in telecommunications. Steven's overall goal is to become a producer for television shows or movies. Steve aspires to create a documentary to increase awareness of bleeding disorders.

Olivia completed her sophomore year and is pursuing a major in pre-med biology. Olivia is working towards a career as a pediatric hematologist.

All attendees who reside or are treated in Ohio, attend FAMOHIO the same year, 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 3rd

Morning Session One: Choose one session 9:00am-10:00am-

Exercise for All

By Debbie Shijo, MPT

We all know that exercise is good for us, but what if you have a bleeding disorder? During this session, we will discuss the benefits of exercise, address barriers, and perform exercises that are important for all of us to live healthier, active lives. Come and learn how to be a healthier you!

Audience: All

Debbie Shijo, PT, MPT is a born and raised Buckeye. She received her Bachelor of Science in Exercise Science at the University of Toledo and her Master of Physical Therapy from Chatham College. She is a staff physical therapist at Akron Children's Hospital where she has been employed for 18 years. addition, for the past 16 years she has had the pleasure of working with a wonderfully collaborative team as one of the physical therapists in the Hemostasis and Thrombosis Center at



In

Akron Children's Hospital. During the past 6 summers, Debbie has enjoyed spending time working with the Northern Ohio Hemophilia Foundation's Summer Youth Golf Program where she has the opportunity to interact with kids outside of the clinic setting, providing additional education while helping them learn and adapt a lifelong sport. Debbie was honored to be a speaker at Hemophilia Federation of America's 2018 Symposium.

Medicare 101: Learn about your Medicare benefits and options By Becky Hayward

This session will focus on who is eligible for Medicare, when someone should apply, how someone enrolls, and what choices someone needs to make. The different parts of Medicare including Part A, B, D, Medicare Advantage and Medicare Supplemental Insurance will be reviewed. We will also discuss different assistance programs and resources available. Come and solve the Medicare mystery!

Audience: Patients/Caregivers

Becky Hayward is the Volunteer Ombudsman for OSHIIP – the Ohio Senior Health Insurance Information Program. Becky joined OSHIIP in 2006. Her responsibilities include overseeing the OSHIIP Volunteer Advisory Board (OVAB), and serving as the primary contact in the home office for over 600 OSHIIP volunteers. Becky also handles the online training for new volunteers, and the monthly webinar refresher trainings for current volunteers.



In addition to her in office duties, Becky is part of the OSHIIP speaker's bureau, which addresses topics pertaining to Medicare including Medicare Parts A, B, D, Medicare Advantage and Medicare Supplemental Insurance.

Becky has a B.A. from Ohio Wesleyan University with a major in Journalism.

She worked in radio and television for 12 years in Tiffin, Tolerand Columbus. She lives in the Columbus area with her husband and son.

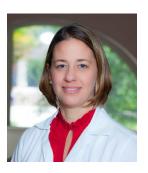
Choose to take Control

By Maria Santaella, MSN

Being a good consumer is more than just access to products and care, it is also about knowing the do's and don'ts that impact your daily life with a bleeding disorder. Being a good consumer also includes understanding your disease, choosing a care team, clearly communicating your needs, and accepting responsibility for making the decisions that ensure your safety and wellbeing. During this interactive presentation, we will discuss tips, tricks and tools available to help you become a better self-advocate and an overall good consumer.

Audience: All

Maria Santaella is a board certified hemostasis nurse with a BSN degree in Nursing and a Master degree in Nursing Education. Before accepting the position as the Research Nurse for the National Hemophilia Foundation she was the nurse coordinator for the University of Miami's Hemophilia Treatment Center for 15 years. She is passionate about educating consumers and their families and thoroughly enjoys contributing to research. Maria recognizes both as being essential in improving the lives of those in the bleeding disorders community. She is fluent in both English and Spanish.



SATURDAY, AUGUST 3rd

Morning Session Two: Choose one session 9:45am-10:45am

Medical Marijuana

By Maria Santaella, MSN

Marijuana is increasingly legal and used as a remedy for pain. This workshop will explain what people with bleeding disorders need to know should they be considering medical marijuana as part of a pain treatment plan. This session will help you discern if this treatment is right for you.

Audience: All

New Products and the Future of Hemophilia Treatment

Dr. Riten Kumar

Hemophilia treatment and care are evolving at a fast pace. Come to this session to explore what is present now and what treatments may be instore in the future. Dr. Kumar will review the methods of action for the newer products and give the audience a look into how treatment may be changed accordingly. This session will provide a look of where we have been and where we are going! Come

to keep abreast of the exciting changes!

Audience: All

Riten Kumar, MD, MSc, is the Associate Director for the Pediatric Hemostasis and Thrombosis Fellowship, a photosom in the Hematology/Oncology and BMT Clinic at Nationwide Children's Hospital and an Associate Professor of Pediatrics at The Ohio State University College of Medicine.

After realizing his passion to further study benign hematology, Dr. Kumar completed a pediatric hematology-oncology fellowship at the Mayo Clinic in Minnesota while receiving a Masters in Clinical and Translational Science from the Mayo School of Graduate Medical

Education. In addition, Dr. Kumar completed a second fellowship in Pediatric Thrombosis and Hemostasis at the Hospital for Sick Children, University of Toronto, Canada. He joined Nationwide Children's in

July 2013. In collaboration with Bryce A. Kerlin, MD, Dr. Kumar created the Joan Fellowship in Pediatric Thrombosis and Hemostasis to train future physicians in hematology.

Dr. Kumar was the recipient of the Young Researcher Award (2014-2015) by the World Federation of Hemophilia and the Eberhard Mammen Young Investigator Award (2014-2015) by Seminars of Thrombosis and Hemostasis. He is also a recipient of the Hemostasis and Thrombosis Research Society, Mentored Research Award (2016-2018).

Sharing your Story: Advocacy in the Bleeding Disorder Community

By Honey Blankenship, MSN, MBA, RN, CCM, CPN

Everyone has a story to tell. It is important to be able to share a strong story beyond the bleeding disorder community. Come learn how to improve your self-confidence so you can effectively increase awareness of bleeding disorders and help improve access to high-quality healthcare. This program discusses the critical elements of a

compelling story and helps attendees develop their own story through effective communication skills.

Audience: All

Honey has been is a Senior Clinical Specialist with Takeda since September 2018. Prior to joining the Takeda team, Honey spent four years managing a case management team at the Cincinnati Children's Hospital. Honey also spent four years as a Nurse Care Manager at the Cincinnati Children's Hospital Hemophilia Treatment Center. During that time Honey enjoyed educating patients and families and advocating for the bleeding disorder community.

Honey received a Master's in Nursing Leadership and Management and a Master's in Business Administration from Walden University. Honey is also a Certified Case Manager and a Certified Pediatric Nurse.

SATURDAY, AUGUST 3rd

Plenary Session - Advocacy in Action! 1:30 -2:30pm

Do you think you are not savvy enough to be a bleeding disorder advocate? Is talking with legislators an experience that scares you? Come to this session and meet parent advocates and hear their stories. The Advocacy Ambassador Panel will discuss the importance of advocacy and share their experiences. These advocates will explain how to tell an impactful story to lawmakers and legislators that can effectively create change.

Audience: All

Panelists: Casey Weidner, Lindsay Lloyd, Elizabeth Skaggs, Beth Liston

Moderator: Jodi Skinner

Information is provided for general information purposes only. FAMOHIO does not engage in the practice of medicine and under no circumstances recommends particular treatment for specific individuals. For diagnosis or consultation on a specific medical problem, FAMOHIO recommends you contact your physician or local hemophilia treatment center (HTC). FAMOHIO does not recommend particular treatment for specific individuals and recommends that you consult a physician before pursuing any course of treatment.



Colorado-based Mountaineer Chris Bombardier has never let hemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with hemophiliac filmmaker Patrick James Lynch and his award-winning production team at Believe Limited to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

In his home state of Colorado, filming captured Chris's training, interviews with Chris, his wife and family, and his hemophilia clinicians. In Nepal, production followed Chris to meetings with Nepalese hemophilia advocates and clinicians as well as to the homes of patients and families affected by the disease, where Chris heard the emotional stories of pain, suffering, and loss related to hemophilia. Production remained with Chris during his two months on Everest, capturing both the physical, psychological, and emotional struggle of acclimating to the mountain and preparing for the greatest challenge of his life, all with the eyes of the global hemophilia community watching.

Leveraging powerful archival footage, the film also chronicles Chris's incredible six-year journey of climbing the Seven Summits, the highest mountain on each continent, during which he receives his "wake-up call" about hemophilia in developing countries and begins his activist mission.

In Nepal, as in nearly all developing nations, there is no routine access to healthcare and lifesaving medicine for people suffering from hemophilia. Bombardier Blood is an inspiring and heart-warming adventure film that cinematically highlights both what is and is not possible when living with this rare disease, depending on a patient's access to medicine and care.

WOMEN'S COMFORT ROOM

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

Cookie Decorating 101

- Two sessions available on Friday:
 - 7:30—8:30
 - 8:45—9:45

Class will be located in the ballroom after dinner — only 40 participants per class

Sign up at check-in

MUST BE 18 YEARS OLD TO ENTER



Learn to decorate cookies using royal icing!

- Grab an after-dinner refreshment of coffee, tea, water or lemonade
- Decorate your own cookies. Each participant will learn to decorate a coffee cup, donut, and a fancy heart. All cookies will be ready to eat once finished
- Chat with the girls and catch up with friends
- Take a break from the kiddos—this is adults only
- · Relax and have fun!

Featuring:



Northwest Ohio's Premier

Cookie Artist

www.laureleas-sweets.com Facebook.com/laureleas Instagram: laureleas_sweets

INFANT'S PROGRAM

The Infant's Program for children 3-35 more than the 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 3rd at 8:30 am and closes at 11:45am for lunch. Parents will be responsible for care and feeding of lunch. Infants can be returned so parents can attend the afternoon session. Pick-up is then at 2:30pm.

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 3rd 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 I-II. 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 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 staff, will provide educational and recreational programming for the youth.



YOUTH PROGRAM CONTINUED

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 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.

TEEN PROGRAM

The Teen Program is for participants ages 13-17. Michele, Larry, and Nick Robben have been in charge of the Teen Program for over a

decade. Michele and Larry have degrees in education and have extensive experience teaching children of all ages. The program will again feature the popular Saturday night raffle. Don't miss out! Check the flyer for further details.

Teen Program Hours:

Friday, 8pm to midnight & Saturday, Noon to midnight

From 9am until Noon on Saturday, the Teens will have an opportunity to participate in Breaking Through, presented by Believe LTD in the Franklin Room

2019 Chapter Program

BREAKING THROUGH!



CASCADE HEMOPHILIA CONSORTIUM

www.cascadehc.org



TAKEDA (SHIRE) www.Takeda.com





APTEVO

http://aptevotherapeutics.com

BAYER HEALTH CARE

http://pharma.bayer.com



CSL BEHRING

https://www.csl.com/



SANOFI GENZYME

www.sanofigenzyme.com



NATIONWIDE CHILDREN'S HOMECARE

https://www.nationwidechiles.org/specialties/homecare

ACCREDO

https://www.accredo.com/

AKRON CHILDREN'S 340 B FACTOR PROGRAM

https://www.akronchildrens.org

BIOMATRIX SPECIALTY PHARMACY

https://www.biomatrixsprx.com/

CINCINNATI CHILDREN'S HOMECARE PHARMACY

https://www.cincinnatichildrens.org/service/h/home-care

COTTRILLS PHARMACY

https://www.cottrillspharmacy.com/specialty-pharmacy.html

CVS/CAREMARK

https://www.caremark.com

GENENTECH

https://www.gene.com/



GRIFOLS

https://www.grifols.com/

NOVO NORDISK, INC

https://www.novonordisk-us.com/

OCTAPHARMA

https://www.octapharma.com

PFIZER HEMOPHILIA

https://www.pfizer.com

SPARK THERAPEUTICS

http://sparktx.com/

UNIQUIRE

http://www.uniqure.com/

DAYTON CHILDREN'S

COLBURN-KEENAN

Please plan to wear your t-shirts on Saturday to the Zoo. You may wear them all day as well.

We plan to try to do a group photo at the Zoo after dinner, around 6pm, and would love everyone to be wearing them!

Schedule

3:45pm Buses begin leaving

4:00pm Zoo opens to FAMOHIO

5:00pm Dinner

6:00pm Group Photo

7:00pm Dessert (S'more bar) 7:45pm Animal Presentation

All activities will take place in Lakeside Pavilion. You are free to walk around the Zoo at your leisure.

Buses will begin leaving after dinner – but only when full.

The last bus will leave after the Animal Presentation.

The Zoo will have scooters to rent for \$35 (based on availability).

BOARD MEMBERS

President

Tina Asco'ugh

VP Planning & Les Gutter Scholarship Chair

Sandy Hibner

VP Treasurer & VP Fundraising

Coy White

VP Legal

Rick Sites

VP Community Outreach Coordinator & Fundraising Committee

Jodi Skinner

draising Committee kinner



TRUSTEES

Charmaine Biega Linda Casto Dwanna Rutter Stephanie Sibrel

Event Coordinator

Lisa Raterman



Secretary & Scholarship Committee

Monica Snider

Les Gutter Memorial Scholarship Committee

Marge Gaffin

Event Co-Chair Irene Boehlefled

Kathleen Cadmus Ralph Gruppo, MD Teresa Rutter



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.

It is with the support of these companies that we are able to provide the education we do. Please stop by and thank them!



FAMOhio.org

<u>FAMOhioInfo@gmail.com</u>
614-344-1075



