

HBDA QUARTERLY NEWSLETTER

Spring Edition 2023

Volume 57

Van Rushton, Chairman

Vicki Jackson, Executive Director

Table of Contents

Cover Page

Words from the Board

Page 2

Annual Meeting 2023

Page 3

Annual Meeting 2023

Page 4

Camp Clot Not Save the Date 2023

Page 5

School Supply Assistance Program

Page 8

World Hemophilia Day 2023

Page 10

MAJOR HBDA ANNOUNCEMENT

Page 11

Summer Activity and Recipe

Page 12

2023 Event Dates

Page 13

Children's Harbor Informational

Page 14

Camp Harvest Save the Date 2023

Page 16

HBDA Information & Birthdays



Hemophilia and Bleeding
Disorders of Alabama, Inc.

Staff

Executive Director

Vicki Jackson

Consumer Relations Manager

Amanda Jennings

Board Members

Van Rushton - Chairman

Leslie Bailey - Treasurer

Tyler Blair - Secretary

Jared McLaughlin - Board Member

Rick Dinkins - Brig. Gen. USAF (Ret.)

Brian Ward - Past President

Chris Blair - Past President

Words from the Board

HBDA's Annual Meeting was once again a huge success!

I always love to learn about the advances being made in Hemophilia treatment and the weekend did not disappoint!

The keynote speakers were outstanding. I saw through the eyes of Ryan Moulton, what it is like to grow up with severe Hemophilia. He shared his story and told us that "no one is defined by this disease state" and that we should be optimistic about the great strides being made every day in search of a cure.

One of my favorite speakers is Dr. Tami Singleton. Every time I hear her speak, her passion for making a difference is evident. She speaks in "layman's" terms about what's happening in the world of gene transfer therapy. This exciting new treatment for bleeding disorders may very well be a game changer for those living with Hemophilia B.

I was humbled listening to Jonathan James, the founder of Hope Charities. He has weathered a lot of challenges in his life and instead of being bitter, he chose to better the lives of those living with Hemophilia. He is determined to create ways to reduce unnecessary suffering for people with rare diseases and chronic illnesses. He was amazing!

The weekend was also filled with fun events that allowed families to fellowship with each other, sharing their stories.

And in great HBDA style, the Saturday night Family event had everybody walking around saying "arrgh matey" at a Pirate themed party! A good time was had by all!

Maybe by next year's Annual Meeting, we will be one step closer to a cure. After all the information I heard at this year's event, I am encouraged that we are getting closer to the miracle of a cure. We can all hope.

Regards,

Leslie Bailey
HBDA Treasurer



HBDA ANNUAL MEETING 2023



HBDA ANNUAL MEETING 2023



Left Page: All of the fantastic sponsor display tables at our Annual Meeting!

Right Page:

Top Row: One of our amazing mother and son duo's, Amy and Cole Croushorn giving a beautiful story of struggle, faith, beauty, teamwork, and redemption with a little bit of Orange and Blue Auburn pride sprinkled in! What a story they told.....never give up on your dream!

Middle Row : Dr. Mike giving an incredible talk on joint health, and then completed his session with a demonstration on how to properly apply KT tape to assist with pain!

Juli Mason and Victoria Tajeda-Martinez giving an eye-opening presentation on Mental Health and Behavioral Needs in children.

Ryan Moulton presenting on his story and journey with Hemophilia.

Bottom Row: Jonathan James with Hope Charities giving an informative presentation on current legislative issues and how we can advocate for change.

Sonya Bross and a patient advocate giving her story and how changes in the hemophilia medications has made such a difference for her family.

Vicki Tuggle, Children's Harbor COO speaking on how valuable their partners are and defining how Children's Harbor was developed and the bright future ahead!

Finally.....our amazing pirates giving a teaser for what is to come at Camp Clot Not 2023!



CALLING ALL SWASHBUCKLERS!

PIRATES ARE TAKING OVER CHILDREN'S HARBOR
AND WE NEED YOUR HELP!



WHEN:

JUNE 17 – 22, 2023

WHERE:

**CHILDREN'S
HARBOR**

Applications have gone out through JotForm! Please check all folders, including spam, to make sure you received it!

If you didn't receive it and would like to discuss further, please give us a call at 334-577-0125 or email at amandajennings525@gmail.com!



HBDA will be bringing back our School Supply Assistance Program this year and it will launch sometime around July. I know school is just closing for the summer, but we wanted to remind you to keep an eye open for this helpful program.

We will be sending applications once we confirm the date for the tax-free weekend. This will ensure that you receive your gift card in the mail prior to that date.

Just a reminder of who this applies to:

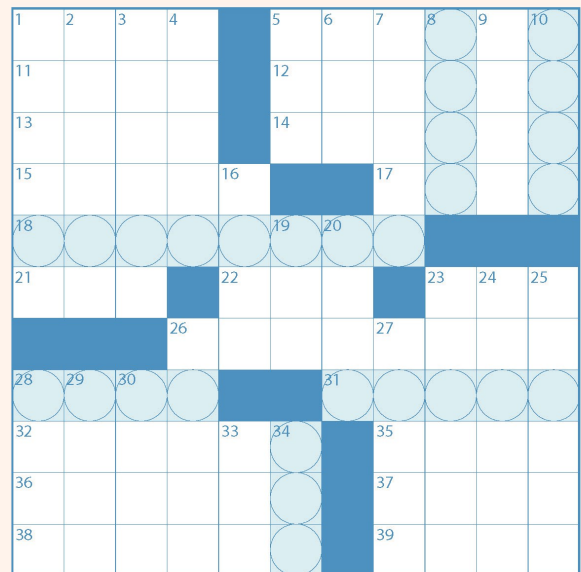
Affected families with children attending K4 – 12th grade for the 2023-2024 school year will be eligible. Homeschool children are included in this, but will have to give the name of their curriculum to be eligible.

We hope everyone has a safe and happy summer! We also want to offer a big Congratulations to our graduating seniors as well as all of the kiddos for making it through another school year!



CAN YOU SOLVE **FOR A DIFFERENT** **HEMOPHILIA A** **TREATMENT?**

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

† Number of people with hemophilia A treated as of October 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than _____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. Mts, 26. passport, 28. zero, 31. three, 32. ewer, 35. Oreo, 36. arrose, 37. tall, 38. lessen, 39. oles, 40. CPU, 4. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polo, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Down: 1. catchy, 2. adore, 3. serum, 4. kneel, 5. CPJ, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. Mts, 26. passport, 28. zero, 31. three, 32. ewer, 35. Oreo, 36. arrose, 37. tall, 38. lessen, 39. oles, 40. CPU, 4. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polo, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2021 Genentech, Inc. All rights reserved.

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.
©2022 Genentech USA, Inc. All rights reserved. M-US-00011998(v2.0) 03/22

Genentech
A Member of the Roche Group

WORLD HEMOPHILIA DAY 2023

April 17th 2023 is the 34th anniversary of World Hemophilia Day, an initiative led by the World Federation of Hemophilia (WFH) to raise awareness and support people living with hemophilia and other inherited bleeding disorders. As a committed partner to rare blood disorders communities, we are proud to collaborate with local patient advocacy groups and host events for patients and their families to recognize World Hemophilia Day together as a community. An important part of building awareness for World Hemophilia Day is WFH's "Light It Up Red!" campaign where landmarks in cities and towns around the world will light red to show support for the global bleeding disorders community.

We sincerely want to thank Shawana Darnell, our local Sanofi representative for requesting the Montgomery and Mobile RSA Towers be illuminated in red for World Hemophilia Day 2023!



sanofi



Montgomery RSA Tower



Mobile RSA Tower



Join us in sharing the power of protection.

This **World Hemophilia Day**, come together with your hemophilia family to learn about the science behind factor activity levels and bleed protection—and explore the possibilities that protection may bring.

A Hemophilia and Bleeding Disorders of Alabama, Inc. & Sanofi Event

This community event is sponsored by Sanofi in collaboration with your local chapter, which does not recommend one manufacturer product or specialty pharmacy over another. Please contact the chapter for additional information.

© 2022 Genzyme Corporation. All rights reserved. Sanofi is a registered trademark of Sanofi or an affiliate.
MAT-US-2209793-v1.0-12/2022

sanofi



After 5 years, it was time to say farewell and move on to our new location! We are excited that we will now be 5 minutes from Children's Harbor! With 3 of our events being hosted at Children's Harbor, the location could not be better!

Our new phone number and mailing address are below!

NEW Phone Number: 334-577-0125

NEW Mailing Address:
HBDA, Inc.
PO Box 241090
Eclectic, AL 36024

NEW Physical Address:
HBDA, Inc.
8426 Kowaliga Road
Eclectic, AL 36024

CLOT Line Assistance Program

Members:

If you are going through a difficult time, please remember, your HBDA family is here for you!

If you need assistance due to an unexpected circumstance, please reach out to us.



SUMMER ACTIVITY & RECIPE!

TASTE SAFE CHALK PAINT DIY



Maybe my favorite discovery ever! How freaking cool is this? I love this paint recipe so much, it is taste safe, easy to make, washable and so vibrant! I mean can you believe it is also made with taste safe items for those curious toddlers that bring everything into their mouths! Can you feel my excitement? My girls have been having the best time with this.

It is so easy to make, you should try it and then take it outdoors for some chalk painting with the little ones! Paint on anything and just hose down afterwards, washes off really easily. Check it out!

YOU'LL NEED:

2 tbsp [corn starch](#)
4 tbsp water
[Food coloring](#)

INSTRUCTIONS:

1. Add the cornstarch, water and food coloring to a small bowl or cupcake pan and mix well.
2. Paint with it

Seriously, that's it! So easy, quick and simple to make, but so fun and can make for a very long lasting activity for your little ones to play, create and learn outdoors!

[ACTIVITIES](#) FEBRUARY 28, 2021

[WASHABLE OUTDOOR CHALK PAINT | MOTHERCOULD](#)

Frozen Banana Yogurt Pops



Ingredients

- 3 bananas peeled and cut in half
- 3/4 cup vanilla yogurt or flavor of your choice
- sprinkles or toppings of your choice
- popsicle sticks

Instructions

1. Halve and peel each banana. Insert a popsicle stick into each banana half.
2. Dip bananas into yogurt, using a spoon to coat each banana evenly. Let excess yogurt drip off.
3. Add sprinkles or topping of your choice.
4. Place bananas on a plate covered in wax or parchment paper. Freeze until the yogurt has hardened, about 2 hours. (Allow for more time if you would like the banana to be frozen through).

[Frozen Banana Yogurt Pops | 3 Ingredients! - The Produce Moms](#)

2023 EVENT DATES AND LOCATIONS

<u>Event</u>	<u>Date</u>	<u>Location</u>
Annual Meeting	March 17 - 19, 2023	Auburn/Opelika Marriott
Camp Clot Not	June 17 - 22, 2023	Children's Harbor
Camp Harvest	October 20 - 22, 2023	Children's Harbor
Golf Tournament	November 10, 2023	Robert Trent Jones Prattville
Year End Luncheon	December 9, 2023	Children's Harbor

We will also have a host of Educational Dinners with presentations throughout the year in 2023, including some in the first few months of the year. Please keep an eye on your email for more details on all of our upcoming events.



CHILDREN'S HARBOR FAMILY CENTER

"THE HARBOR"

Anchored in Hope. Strength in the Storm.



Children's Harbor provides respite and resources to families with children who have experienced a life-altering medical diagnosis. The families we serve seek a safe refuge when faced with unexpected life circumstances. The Family Center at the Children's Hospital, "The Harbor," meets the families where they are by providing care services to inpatient and outpatient children, caregivers and siblings.

The Harbor is designed to help strengthen families with children facing a life-altering medical diagnosis through refuge, respite and resources anchored in hope. Children can connect with others with similar diagnoses for a sense of community and camaraderie, while parents can escape to The Harbor and leave the noise and activity of the hospital rooms behind to find solace.

SERVICES PROVIDED AT NO CHARGE

FOR THE FAMILY



- Kitchen
- Lounge
- Nap Rooms
- Salon
- Library

FOR THE KIDS



- Basketball Court
- Game Room
- Toddler Play Area
- Arts & Crafts
- Story Time

FOR THE PARENTS



- Business Center
- Fitness Center
- Laundry Unit
- Shower

WHERE WE ARE

Second floor of Children's of
Alabama hospital

1600 6th Avenue South, Suite 200

Open Monday through Friday
8:30 a.m. to 5:00 p.m.

Closed everyday from
noon to 1:00 p.m. for lunch

LEARN MORE



COME VISIT FOR A TOUR

205-638-6123
www.childrensharbor.com



@childrensharbor



Add our date to your calendar now so you don't miss this amazing event!

"Camp Harvest" Family Educational Weekend is one you don't want to miss!

**Mark your calendar for October 20 -22, 2023 at
Children's Harbor on Lake Martin.**

It's a time to catch up on what is happening and what WILL be happening in the world of bleeding disorders, with informative sessions from industry partners and top keynote speakers.

Plus, you will have time to re-connect and bond with your HBDA Family and Industry Representatives.

It is an opportunity to be part of some of HBDA's favorite Fall traditions: Family Portraits, hot chocolate and cider around a roaring campfire, arts and crafts, our annual Family pumpkin carving contest for bragging rights and so much more!





ELOCTATE

[Anti-hemophilic Factor
(Recombinant), Fe Fusion Protein]

**JOIN THE CONVERSATION.
LEARN ABOUT ELOCTATE.**

Sanofi Community Relations and Education Managers (CoRes) have years of experience working with patients on ELOCTATE and can provide you with helpful resources and support.



MEET YOUR CoRe, SHAWANA DARNELL

Serving AL & GA

"I love partnering with families in the hemophilia community. I start each day looking for new connections and the opportunity to say yes."

Shawana.Darnell@sanofi.com
(404) 796-0084

[Contact](#) your local CoRe

sanofi

© 2023 Genzyme Corporation. All rights reserved. ELOCTATE is a registered trademark of Bioverativ Therapeutics Inc., a Sanofi company.

MAT US 2020799 v1.0 10/2020

HBDA INFORMATION

Address: 8426 Kowaliga Road, Eclectic, AL 36024
PO Box 241090, Eclectic, AL 36024

Phone: (334) 577-0125

Fax: (334) 577-0127

Website: www.hbda.us

Facebook: www.facebook.com/hbda4u



BIRTHDAY BLESSINGS

May

Maxwell McLaughlin
Rexanne Johnson
Davie Jane Wood
Bonnie Utterback
Tayla Cooper
Amy Croushorn
Libby Hall
Evan Ward
Dennis Jones
Jack Mason

June

Jeremy Donahoo
Taylor Renfroe
Chandler Ward
Jhonathan Davis
Carla Vickery
Carver Bailey
Christian Hall
Hunter Abrams
Jackson Sanders
Alex Leonard
Harmony Pressley
Isabella Sandow
Cole Croushorn
Keshawndra Cooper
Haley Jones
Gavin May
Maddie Sanders
Keondre Cooper
Micaela Caro
Taj Deloach Offiong

July

Rebecca May
Natarra Waters
Edward Masline
Sarah Blyden
Connie Grammer
Pat Morgan
Christine Chung
Dana Abrams
Carmen Lewin
Nelton Davis
Tera Bradshaw
Haley Harris
Andrew Walls
Matthew Watts
Royal Smith, Sr.
Ann Mitchell
Brittnee Vasil
Noah Reid Guadalupe