HBDA QUARTERLY NEWSLETTER

Fall Edition 2020

Rick Dinkins, Chairman

Volume 47

Vicki Jackson, Executive Director

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HBDA Information



Staff

Executive Director

Vicki Jackson

Consumer Relations Manager

Amanda Jennings

Board Members

Rick Dinkins - Chairman Jared McLaughlin - Vice Chair Van Rushton—Treasurer Blake Harris

Brian Ward - Past President Chris Blair - Past President

Words from the Chair

College football is underway, Fall is here, Thanksgiving and Christmas are just around the corner and the CORONA virus is still with us. College football will end in January, Fall will turn to Winter, the Holidays will give way to the New Year **AND** our "friend" CORONA will still be here! I hope I'm wrong; but, given how 2020 has turned out so far, I'm guessing I'm correct. But one thing I am sure about is that your HBDA staff continues to work hard on your behalf despite this year's difficulties.

As I write this, Vicki and Amanda are organizing the HBDA Annual Golf Tournament in Prattville. The tournament is a major fundraiser for HBDA and is always well received. Our funding has been a challenge this year but thanks to Vicki and our accounting firm, we have been able to take advantage of several federal and state grants. Our industry partners have been extremely helpful as well hosting virtual meetings and training on several occasions.

The staff is starting our 2021 planning and we'll be ready for whatever comes our way. There are so many unknowns, but we want to be prepared to move forward with a full slate of programs and events for the year. Let's all pray that we return to some state of normalcy soon.

Another wildcard for 2020 is this year's national elections. Regardless of how it turns out, we all need to be tuned in to changes in insurance programs and funding. Health care costs garner a lot of attention and we all need to be very mindful of what's going on.

As I wrap this up, let me say Happy Holidays to all of you. While this year has been challenging, we are more fortunate than many others in this world. Debby and I are so grateful and blessed. We hope you feel the same way.

Rick Dinkins Chairman, HBDA





Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN

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New Addition to the HBDA Board





Welcome to the HBDA family!

Blake Harris is a sales professional and entrepreneur, currently serving as an Account Executive at Xerox Business Solutions as well as the owner of Inflatables of Montgomery since 2013. Blake has a background in marketing, with 11 years of experience in consulting with company officials, sales departments, and advertising agencies to develop promotional plans and marketing strategies.

Blake grew up in the Phenix City Alabama, moving to the river region in 2006 to play baseball at Auburn University at Montgomery, where he has since resided. He obtained his Bachelors in Business from Amridge University in Montgomery in 2014. During college, he met and married his lovely wife, Lindsey, and together they have four children: three girls Berkley (12) Harper (6) Chandler (5) and one boy Shepherd (1). Blake is a devoted husband and father above all else. Outside of work, Blake has served as a deacon at Vaugh Forest Church in Montgomery, AL, where his family has attended church for the past 9 years.

Blake is passionate about both personal and professional development and leads by example, pulling those around him in a positive trajectory. He looks forward to joining HBDA to make a difference in lives affected by hemophilia.

Annual Meeting Series Update

Throughout the course of the 6 week period between July and September, many of our members logged on to Zoom and actively participated in the educational sessions given by our Pharmaceutical partners as well as some "Member Happy Hour" sessions given by our Specialty Pharmacy partners. The series was long, but we appreciate the support and dedication of our members during this transitional time. We know this has not been an easy year for many in our community, so we humbly thank you for taking the time out of your evenings to learn and fellowship with your bleeding disorders community. To show our appreciation and support to our community, HBDA provided a \$100.00 cash prize at the end of each of the sessions with the chance to win a \$1,000.00 cash grand prize at the end of the entire series. At the end of each session, we watched the wheel spin with anticipation and celebrated when the winner popped up on the screen! The cheers from all attendees as we celebrated the winner was such a blessing to see, and it blessed us at HBDA to be able to give back to our members in such a difficult time. We want to take this time to say thank you for your support, that we love each and every one of our members, and we are counting down the days until we can hug each one of you and see you face to face again.

Congratulations to all of the winners, and a special congratulations to Carla Vickery, who won the \$1,000 Grand Prize!







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Make First Choice your first choice

HBDA 2020 GOLF TOURNAMENT



Attention All Golfers!
Don't "fore-get" to register
for HBDA's 2020 Golf Tournament!

Registration - 10:00 AM Lunch - 10:30 AM Tee Off - 12:00 PM



HBDA's 12th Annual "Tee It Up for Hemophilia" Golf Tournament November 13, 2020

at one of the jewels in the River Region's crown, The Robert Trent Jones Golf Trail at Capitol Hill in Prattville, Alabama.

Join us in this fun filled day of golf and probably some good-natured ribbing between our golfers.

HBDA's tournament is so much more than just golf!

You will have a chance to win fabulous gifts, enjoy an afternoon of spending time with your friends, a delectable lunch, and awards. To top the day off, we will have a fabulous wrap up cocktail soiree, and who knows, maybe even say hello to a celebrity or two!

Stay tuned for more information from HBDA regarding this event!











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

 — cough up blood

 - pain or redness in your arms or legs shortness of breath

 - chest pain or tightness
 fast heart rate
- cough up bloodfeel faint
- headache - numbness in your face
- eye pain or swellingtrouble 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

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
- 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.

- 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
- 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
- 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?" $\label{eq:lemmation} % \begin{subarray}{ll} \end{subarray} % \begin{$

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- ioint 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).
- · 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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and

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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: 10/2018



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More than 20 years* of experience—the first recombinant treatment for individuals with hemophilia B



Dosing options to meet your needs—for once-weekly prophylaxis and on-demand use



Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix



The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is NOT used to treat hemophilia A.



ASK YOUR DOCTOR WHICH BENEFIX
DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.





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Ronly

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing fast heartbeat
difficulty breathing swelling of the face
chest tightness faintness

turning blue rash (look at lips and gums) hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.







Go to www.GotHemophilia.com to get your complimentary T-shirt. (while supplies last)



*enter the code below to complete your T-shirt request

HBDA2020









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CLOT Line Assistance Program

Members:

In this unprecedented time, please remember that we are here for you!



If you have been affected by COVID-19, or if you need assistance purchasing school supplies for your kids, please reach out to us.





20 Educational Presentations

* All sessions are virtual unless specified otherwise

Date of Presentation:	Company Presenting:	Time of Presentation:
November 5, 2020	Novo Nordisk (LIVE - more details to come soon for Montgomery)	6:00 PM - 8:00 PM
November 10, 2020	Sanofi Genzyme	6:30 PM - 7:30 PM
November 18, 2020	Takeda	6:30 PM - 7:30 PM
December 1, 2020	Novo Nordisk (LIVE - more details to come soon for Birmingham)	6:00 PM - 8:00 PM
December 3, 2020	Genentech	6:30 PM - 7:30 PM
December 8, 2020	Takeda	6:30 PM - 7:30 PM
December 10, 2020	Pfizer	6:30 PM - 7:30 PM



In Memory Of Alvin L. Morgan





Alvin Lawson Morgan, 73 of Montgomery, AL went to Heaven Friday March 20, 2020.

He was preceded in death by his parents Buford & Ruth Morgan, his brothers Charles & Ronnie Morgan. He is survived by his wife of 48 years, Pat Grier Morgan; Children, Tisha (Brian) Ward & Blake Morgan; Grandchildren, Evan, Chandler, Jessica & Dylan Ward. In lieu of flowers donations may be made to Mulder Memorial United Methodist Church or Hemophilia & Bleeding Disorders of Alabama.

A few words from Pat Morgan:

Alvin's Celebration of Life was 8/29/20, Our 49th Wedding Anniversary. Alvin loved his family immensely. He never met a stranger and loved talking. He loved the Hemophilia Community and HBDA. We will miss him attending all the Hemophilia Events.

On behalf of HBDA, we will sincerely miss seeing Alvin at all of our events. He was always willing to listen to everyone and could bring a smile to your face with his stories. We send our thoughts and prayers out to the Morgan and Ward family at the loss of their husband, father, grandfather, and friend. Alvin will remain in the hearts and minds of all who knew him.











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YEAR END LUNCHEON ANNOUNCEMENT:

Due to the continuing Coronavirus pandemic, we are having to cancel our Year End Luncheon in December. We are heartbroken to have to continue to cancel events, but it is best to stay safe. We are keeping all of you in our thoughts and prayers as the holiday season approaches. We are hopeful that we can get a bit back to normal as 2020 comes to a close and 2021 comes into view.

We hope you have a Happy Thanksgiving, a Merry Christmas, and a blessed New Year. We pray you stay healthy and safe and we certainly hope to see you all in person after the new year. Thank you for your support during this trying year and we look forward to serving you in 2021 and beyond.

Keep your eyes open for a special delivery from HBDA coming to you in mid-December.





NO-BAKE THANKSGIVING TURKEY COOKIES

Ingredients

- 1 ½ cups sugar
- ½ cup unsweetened baking cocoa
- 1 stick unsalted butter
- ½ cup whole milk
- 1 cup peanut butter
- 1 teaspoon vanilla
- 3 cups quick 1-minute oats
- 1 bag candy corn
- 60 candy eyes



Instructions

- 1. Mix sugar, cocoa powder, butter, and milk in a medium saucepan, and cook over medium heat.
- 2. Stirring constantly, bring the mixture to a boil, and allow it to boil for two minutes.
- 3. Remove from heat, and mix in peanut butter and vanilla.
- 4. Stir in oats until combined.
- 5. Immediately drop tablespoon-scoops of cookie mixture onto parchment or wax paper.
- 6. Allow to cool slightly, then arrange five pieces of candy corn along the top of the cookie in a turkey feather arrangement.
- 7. Press two candy eyes onto each cookie.
- 8. Cut 30 candy corn pieces in half, and place the bottom half of the candy corn onto a cookie for the beak.
- 9. Be sure to press the candy corn and eyes down firmly enough to get them to stick.
- 10. Set the cookies aside to cool completely to set before serving.



Recipe Source: https://www.shrimpsaladcircus.com/no-bake-thanksgiving-turkey-cookies-recipe/? utm medium=social&utm source=pinterest&utm campaign=tailwind tribes&utm content=tribes

ROLO PRETZEL REINDEER COOKIES

Ingredients

50 mini pretzels (divided)

25 Rolos

25 small round red chocolate candies

50 candy eyes

Instructions

Preheat the oven to 350 degrees.

Separate half of your pretzels and spread them out on a baking sheet lined with parchment paper or a silicone liner.

Unwrap the rolos and top each pretzel on the baking sheet with one.

Cut the remaining pretzels in half down the middle to form the antlers. (A few may break, so its best to have about 10 extra pretzels or so)

Place the baking sheet in the oven and bake for 1.5 to 2 minutes until rolos are soft.

Remove the baking pan and add the nose, antlers and eyes to each reindeer. (I added mine in that order).

Allow the reindeer to cool completely to allow the chocolate to set before eating. (Place pan in the fridge for quicker cooling if desired.)

https://lmld.org/rolo-pretzel-reindeer/



Ingredients

1 banana, sliced

8 strawberries, hulled

1 ounce white chocolate, melted

8 white chocolate chips

<u>Instructions</u>

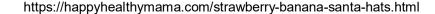
Spread a small amount of melted white chocolate on a banana slice. Press a hulled strawberry into the melted chocolate.

Dip a white chocolate chip into the melted chocolate and place it on top of the strawberry.

Place the "Santa Hat" on a tray. Repeat with the rest of the strawberries and banana slices until all are complete.

Chill for 10 minutes to allow the chocolate to harden.







HBDA INFORMATION

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Website: www.hbda.us

Facebook: www.facebook.com/hbda4u



BIRTHDAY BLESSINGS

November

Jennifer Anderson

Brynlee White

Katie Lee

Cameron Jones

Casey Sanders

Laura Pitman

Trace Lee

Chelynn Pargo

Robin Blair

Brayden Botts

Quintez Renfroe

Myra Cooper

Patsy Lewis

Makaylie Kelley

Grace Chung

Ciara Pargo

Jason Branch

Alexandra Hall

Fantine Martin

Ed Leathers

December

Joseph Clarke

Mary Cathrine Noa

Tricia Watts

Debby Dinkins

Paul Moore

Camdyn Pressley

Kimberly Wood

Daniel Botts

Cheyenne Warren

Dawson Findley

Travis Reed

Amanda Jennings

Michael McElhaney

Leslie Bailey

Kelly Champagne

January

Madilynn Clarke Nathan Sanders

Mary Beth Clarke

David Hall

Marcus Chung

Robert Masline

Jayla Lewis

Amare Banks

Takiya Wells

Bentley Golden

Lauren Killgore

Erin Cotham

Donna Bate

Brayden Crenshaw Carolann Sorrells

Jeremy Jones