HBDA Quarterly Newsletter

Summer Edition 2019
Volume 42
Rick Dinkins, Chairman
Vicki Jackson, Executive Director

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Hemophilia and Bleeding Disorders of Alabama, Inc.

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HBDA CAMP CLOT NOT WAS SHIPWRECKED

JUNE 15 – 20, 2019
ALEXANDER CITY, AL

Children's Harbor on Lake Martin was the scene for Shipwrecked 2019!

At first, when you hear Shipwrecked, you think of danger and destruction. Camp Clot Not was just the opposite. We chose to focus on the positive aspects. Many of our activities were centered around the concept of teamwork and helping each other. We wanted to expose the campers to the idea that they are not alone in their journey with hemophilia. Our vision statement, "No One Bleeds Alone" was on full display this week.

On Check-In day, each camper was greeted by their counselors and LIT's. The campers said goodbye to their family members and were escorted to their cabins to prepare for the fun week ahead. We kicked the festivities off with our traditional beach front Dance Party. Plenty of music was enjoyed by the campers. One highlight of the evening were the yummy sno-cones prepared and served to order. The group was treated to a slideshow of previous camps on the big screen. As usual, there were plenty of laughs and the campers really enjoyed picking out their friends (and younger selves) on the slideshow.

Camp Clot Not 2019

Each day was packed with fun, games and educational opportunities. The fun and games included tons of pool time. Basketball, volleyball, Putt-Putt, oversized yard games, canoeing, swimming in the lake, and time at the playgrounds. The kids were also treated to a huge inflatable Tsunami Slide and Water Balloon Wars. Each group was offered a chance to have a small water balloon fight within their group as an activity. At the end of the week, all of the kids, counselors, LIT's and even some staff members were involved in an epic battle! Over 1000 water balloons were launched across the field. Shrieks of laughter rang all over the campus. On Tuesday, through the generous support of volunteer boaters, Chris and Jennie Zinn, Clark and Erica Goss and others, the campers were able to enjoy a day on an island for lake day. They were treated to boat rides, tubing, swimming, and plenty of fun.

Wednesday night was Awards Night. We began the evening with a wonderful dinner. Following our meal, we kicked off the festivities with our traditional commencement ceremony. Each camper was recognized and presented with their diploma and a copy of the 2019 yearbook.

Camp Clot Not Awards

Later in the ceremony, awards were given to deserving campers. The awards were for the following:

Best 1st Time Camper ~ Clean Camper Award ~ I'll Do It Camper Award ~ Most Spirited Camper ~ Best Mentoring Camper

Counselors Choice for each group ~ Best Overall Camper

Best 1st Time Camper:
Ayden Hoggle

Clean Camper Award:
Brody Dunston

Most Spirited Camper:
Cooper Guadalupe

Best Mentoring Camper:
Cole Croushorn

Counselors Choice -
Crab Cakes:

Makenzie Clarke

Counselors Choice -
Mermaids:

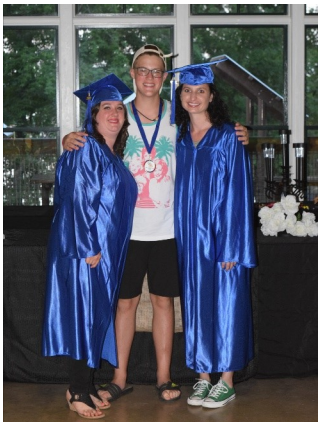
Maddie Sanders

Counselors Choice -
Stingrays:

Tavien Casey

Counselors Choice -
Starfish:

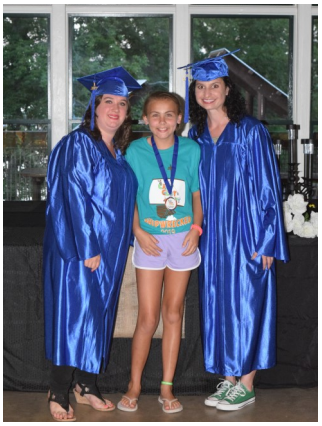
Jack Mason



Counselors Choice -
Sharks:

Nathan Sanders

"I'll Do It" Camper:
Alex Leonard



Best Overall Camper:
Kileeann Warren

Minute to Win It Champions:
Mermaids

Camp Clot Not 2019
Big Stick & Branch Awards

Our fabulous medical team, Nurses Shannon, JD and Christy, were on hand to present the Big Stick Awards and Branch Awards. We are so very proud of the campers that received their Big Sticks this year. All of the campers that wanted to attempt to earn their Big Stick were successful. We had numerous Branch Award recipients. The Branch Award is given to the campers that are able to successfully demonstrate their continued ability to self-infuse. The medical team has specific criteria that each camper must meet in order to receive their awards.


Big Stick - Brody Dunston


Big Stick - Madison Guy


Big Stick - Alexandra Hall


Big Stick - Ayden Hoggle

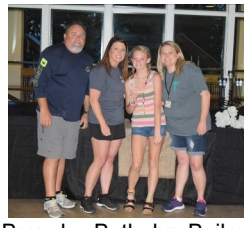

Big Stick - Jeannie McLaughlin


Big Stick - Maddie Sanders


Big Stick - Cheyenne Warren


Big Stick - Killeeann Warren


Branch - Reyn Amos


Branch - Bethalyn Bailey


Branch - Mateo Caro


Branch - Makenzie Clarke


Branch - Jaxson Kelley


Branch - Madison Kelley


Branch - Kristopher Lewis

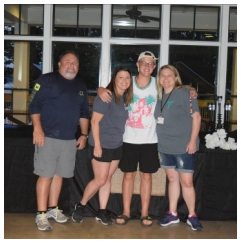

Branch - Alex Leonard


Branch - Troy Littlejohn


Branch - Jack Mason


Branch - Chelynn Pargo


Branch - Taylor Renfroe


Branch - Nathan Sanders


Branch - Alleick Shipley


Branch - Evan Ward

Camp Clot Not 2019 is in the history books but cannot be closed out without a huge thank you to all of the campers, staff, and volunteers that made it such a successful week. We all survived being Shipwrecked because we had each other. Now we can look forward to all of the new adventures that are on the horizon.

Words from the Chair

FOLKS IT'S HOT OUTSIDE!

Here in Central Alabama summer came in with vengeance…not much Spring this year and my electric bill confirms that we are way ahead of previous years. With summer come vacations, getting ready for school and HBDA's preparations for the 11th Annual Golf Tournament on September 13th in Prattville. The tournament is a big event for the chapter and provides a chance for some our sponsors and members to interact on the links while helping us to sustain the chapter for the remainder of 2019.

By the time you receive this, the new website will be up and running and we are anticipating a good "launch." Needless to say, we've had a few struggles along the way (poor performance by our contractor, looking for a new one, etc. etc.) and the desire to make it more useable and friendly for all. I think we have it this time and hope you will agree…please don't hesitate to give us feedback as we move forward.

By all accounts, Camp Clot Not was a big success…even the weather cooperated, and feedback has been very positive. We had 5 first time campers and it sounds like they'll be fully engaged in the chapter from now on.

On a side note, 2019 celebrates the 50th anniversary of the Apollo moon landing and space walk. Alabama played a major role in the nation's space activities and Public Broadcasting TV is dedicating several programs highlighting this state's role. Check it out…great for the kids and wonderful memories for us "old timers" who got to witness the events of the day.

Stay cool and Be safe….

Regards

Rick Dinkins

P.S. SAVE THE DATE FOR FAMILIY CAMP 2019….OCTOBER 25 - 27!!!!!

Here We Grow Again...

HBDA is proud to announce the launch of our new website as part of an ongoing evolution of our brand.

We have redesigned our website to better represent who we are today and to symbolize the bright future ahead.

We launched a new version of our website last September, but due to some issues, we chose to transition to a new developer to reformat and build and ongoing upgrade to our site!

It has been a labor of love, but we are SO PROUD of our new website. It will be instrumental in making our communication with our members more streamlined and registration for our events can now be integrated into our Member Portal.

Please visit us at www.hbda.us to sneak a peek!

HBDA 2019 Golf Tournament

Attention All Golfers!
Don't "fore-get" to register
for HBDA's 2019 Golf Tournament!

Registration - 11:00 AM
Lunch - 12:00 PM
Tee Off - 1:00 PM

Robert Trent Jones Golf Trail
Capitol Hill

For more information, please contact us at hbdaevents@gmail.com or call us at 334-478-7822

HBDA's 11th Annual "Tee It Up for Hemophilia" Golf Tournament

September 13, 2019

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!

HBDA
Hemophilia and Bleeding Disorders of Alabama, Inc.

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

ADYNOVATE® is FDA approved for children and adults with Hemophilia A

PROVEN PROPHYLAXIS + SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE = *moments* YOUR WAY

*ADYNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1,2]

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1]

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor to see if ADYNOVATE treatment may be right for you and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

DETAILED IMPORTANT RISK INFORMATION (cont'd)

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. **3.** Data on file; Shire US Inc.

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

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- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
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The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Issued 05/2018

S47033

Transitioning to College??

On Time Can Be Too Late

Michael Joshua

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

Publication: PEN 8.19
Column: As I See It

Save the Date

For HBDA's

Family Educational Weekend

Mark your Calendars for

October 25 – 27, 2019

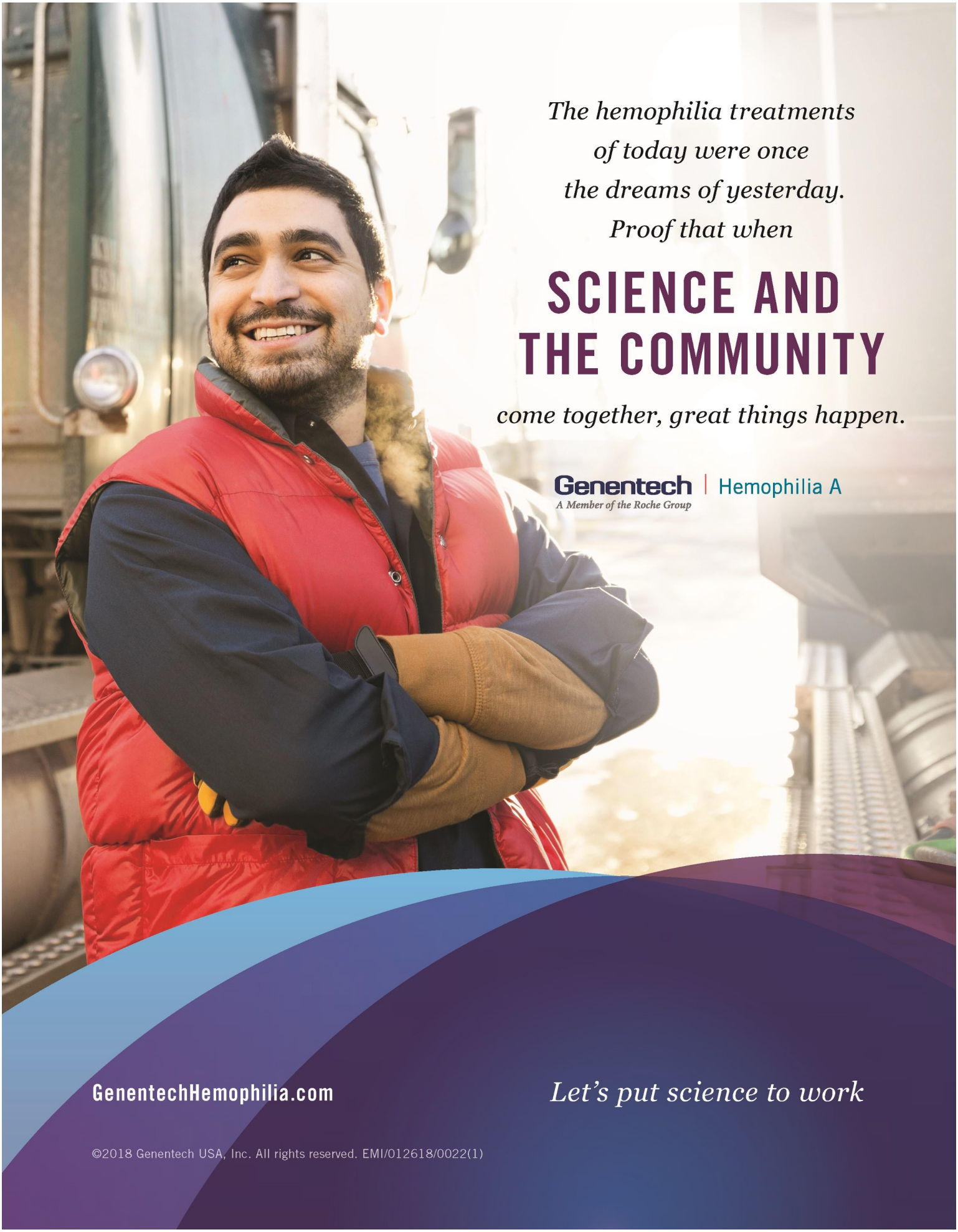
Keep an eye out for more information coming to your inbox soon!

This will be a wonderful weekend full of fellowship and education!

HBDA

Hemophilia and Bleeding Disorders of Alabama, Inc.

CHILDREN'S HARBOR



CSL Behring

Biotherapies for Life™

WOULD YOU LIKE TO GET IN THE GAME??

We are excited to announce that it is time again to apply for CSL Behring's JNC "Gettin' in the Game" Program. You are receiving this email because your affected child meets the criteria to apply for this opportunity. The nominees selected will arrive in Phoenix, Arizona by 12 pm on Friday, November 8, 2019 and can depart anytime on Sunday, November 10, 2019. CSL Behring will sponsor each chapter nominee and 1 accompanying adult to participate in this program. This sponsorship will include the coordination and cost of airfare, ground transportation in Phoenix, Arizona, and hotel arrangements (attendees will be responsible for transportation to and from their hometown airport).

Hotel accommodations and meals are provided as follows:

- Participants will stay at the Scottsdale Resort at McCormick Ranch, 7700 East McCormick Parkway, Scottsdale, AZ 85258
- CSL Behring will cover the cost of 1 hotel room per nominee. Scheduled meals will be provided onsite for registered participants only.

This program was developed by CSL Behring and is the only national Golf, Baseball, and Swimming competition designed specifically for the bleeding disorders community. The JNC features accomplished "Gettin' in the Game" athletes who themselves have been diagnosed with bleeding disorders.

How to participate:

- Chapter nominees MUST be between 7 and 18 years of age and MUST have a bleeding disorder that they are currently being treated for.
- Your local chapter (HBDA) will nominate 2 participants, girls or boys - each one selected for Golf, Baseball, or Swimming.
- Nominees will be selected by a chapter committee based on an essay written and submitted no later than **Monday, August 12, 2019 by 12:00 pm (noon).**
- Essays should be emailed to hbdaevents@gmail.com with the subject line of "JNC Essay Contest Submission".

Your essay should include the following:

- Applicants name, age and gender. Parent/caregiver who will be attending and their contact information including e-mail address and daytime phone number.
- Which sport are you interested in participating in (Golf, Baseball, Swimming) and why?
- How have you been involved in your local chapter?
- What lessons have your learned through your experience of having a bleeding disorder?
- Who in your life has been your biggest influence and why?

Essay submission should be typewritten (parent or caregiver can assist) and should answer the above questions thoroughly. The parent/caregiver will be notified via email to confirm receipt of the essay submission. Upon selection of the nominees, all applicants will receive notification via email of the committees selections.

If your child is selected by the committee, a nomination packet will be sent to you with instructions on how to proceed with registration for this event. We are excited to be able to offer this opportunity to our members and wish you much luck in this process. If you have any questions regarding the JNC National Championship, please feel free to reach out to us. Good luck!

Getting Help at School for Your Bleeding Disorder

When you're at home and you get hurt or feel a bleed starting, you know to go to your parents or another grown-up who takes care of you for help. But it's important to know that if you're hurt at school, you are definitely not on your own! There are adults there, too, who can help you when you need it.

Your School Team

If your school has a nurse, that's the No. 1 person you should see if you fall on the playground or get hit by a ball in gym class, or even if you are just worried you might be having a bleed. The school nurse may not know as much about bleeding disorders as the nurses at your hemophilia treatment center (HTC). But she or he will know what to do, or whom to call, so you get the treatment you need. Some kids keep factor at school and can infuse right there with help from the nurse—and then get back to class in a flash!

If your school doesn't have a nurse or if the nurse isn't available, there will always be another staff member who can help you. It might be the school secretary in the main office, a counselor or a teacher. Your parents and a nurse from the HTC have probably met with these people so they're ready to swing into action and support you. Ask your parents which adults you should seek out if you have a problem.

You Have a Role to Play, Too

While there's a team of adults at school looking out for you and making sure you're safe, no one knows how you're feeling better than you do. If you get a knock or accidentally injure yourself, or your ankle, knee, elbow or another body part starts to hurt or feels warm or bubbly inside, speak up and ask to go to the nurse or one of the other adults at school right away.
Don't feel bad about asking for assistance. Rest assured that everyone at school wants you to feel your best so you can focus on what you're there to do: Learn, grow and have fun!

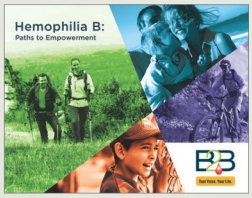
Upcoming Educational Dinners

August 8, 2019	Dinner	Mobile, AL	Grifols
August 22, 2019	Dinner	Pelham/Alabaster, AL	Takeda
August 29, 2019	Dinner	Montgomery, AL	Pfizer
September 19, 2019	Dinner	Montgomery, AL	Takeda
September 24, 2019	Dinner	Location TBD	Genentech
November 12, 2019	Dinner	Location TBD	Genentech
November 7, 2019	Dinner	Mobile, AL	Pfizer

Your requested participation in any of the above dinners MUST be made through an RSVP to Amanda Jennings.
Please call 334-478-7822 or email at amandajennings525@gmail.com
Invitations will be e-mailed in advance through the member portal. If you do not receive an invitation and you wish to attend, please contact the HBDA office.

B2B: Your voice. Your life.

Interested in stories and personal experiences *from* the hemophilia B community *for* the hemophilia B community? Turn to B2B.



Download or view books
filled with patient stories that can inspire, empower, and educate

Listen to podcasts
that capture the voices of the hemophilia B community

View videos
that feature members of the community sharing their personal experiences

And there's much more, too!

More topics include . . .

- Educating your child's school about hemophilia B
- HEMO 101 for caregivers
- Managing relationships with hemophilia B
- Life for girls and women with hemophilia B

VISIT WWW.HEMOPHILIAVILLAGE.COM

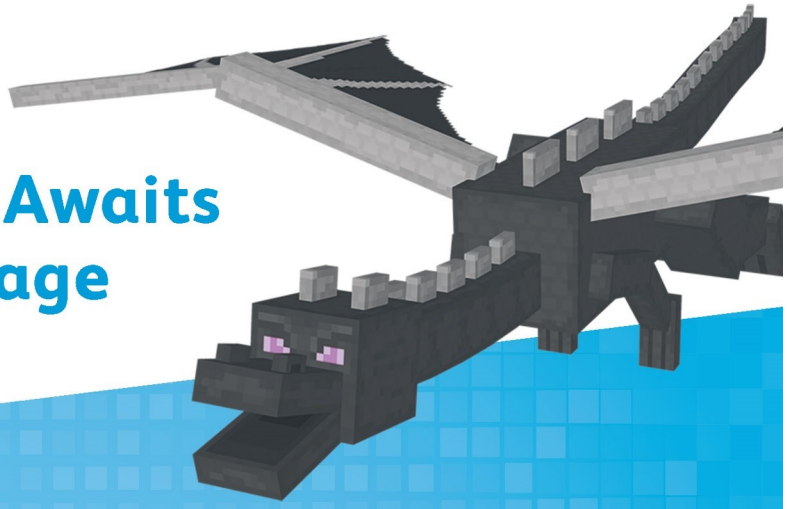
to explore all B2B materials

PP-HEM-USA-1093-03

Printed in USA/September 2018

Pfizer Hemophilia

The Ender Dragon Awaits at Hemophilia Village



HEMOCRAFT™

INFUSION ADVENTURE

Adventure and education in a virtual world

We've blended education with adventure to bring you an experience that emphasizes the importance of staying prepared and sticking to a treatment plan. Craft an infusion kit, keep an eye on your "factor bar," and share your game strategy with friends and family—but beware of the Ender Dragon!

Visit www.hemophiliavillage.com to learn more about HEMOCRAFT and start your own adventure

PP-HEM-USA-1093-01

Printed in USA/September 2018

Pfizer

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

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.

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

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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injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

HBDA Information

Address: 917 W Osceola Street, Wetumpka, AL 36092

Phone: (334) 478-7822

Fax: (334) 478-7824

Website: www.hbda.us

Facebook: www.facebook.com/hbda4u

Birthday Blessings

August

Amy Blair
Terrell Abrams
Jacob Weaver
Kaitlyn Weaver
Dylan Ward
Rocisa Moore
Tikila Hawthorne
Linda Smith
Seth Kelly
Shelia Baird
Rick Dinkins
Kristopher Lewis
Cannan Dickinson
Sally Brooks
Mackenzie Jones
Bella Dickinson
Jeannie McLaughlin
Sean Halloran
Tim Mason
Spring Kane
Ajie Attawia
Doug Amos
Heeyeon Chung
Belita Abrams
Christian Blyden
Jason White
Stanley Moore
Kileeann Warren
Mackenzie Clarke
Jeannie Dickerson
Knox Wells
LaVadre Hawthorne
Robert Bate
Ericka Caro
Chris Blair
Scott Vance
Odin Walls

September

Ayden Hoggle
Madison Kelley
Jaxson Kelley
Jared McLaughlin
Lyric Donahoo
Jessica Ward
Zach Pressley
Mark Osborne
Jasmine Hoggle
Tabetha McGlinchey
Mary Hunter
John Lawrence Masline
Colton Brooks
Gensen Lee
Erica Goss
Jaymee Vowell
Daryl Holland
Vicki Jackson
Kristen Blair
Chesca Barnett
Anna Halloran
Brooke Holland
Abi Dickinson
Lee Hall
Jace McLaughlin
Raley Hoggle
Kristy Roberts
Henry Lee
Jennifer Mason
JD Weir

October

Pat White
Caelum Walls
Nicole Lloyd
Levi McLaughlin
Luke Bradshaw
Chance Abrams
Blake Morgan
Ethan Forsman
Joshua Sorrells
Katelyn Erben
Christian Pressley
Micah Champagne
Justin Clarke
Harper Walls
Jonathan Hall
Rachel White
Fallon Howard
Kyle Robinson
Adam Bradshaw
Royal Smith, Jr.
Jason Kelley
Andy Hall
Tisha Ward
Ethan Fields
McKenzie Lee
Piers Smith