Vital Link



...For Hoosiers Living with a Bleeding Disorder

September 2018

The Vital Link is published quarterly by Hemophilia of Indiana, Inc.

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2018 Hemophilia of Annual Meeting Recap

The 2018 Hemophilia of Indiana Annual Meeting was held August 11th & 12th at the Crowne Plaza Indianapolis-Airport Hotel. With record attendance, the 2018 Annual Meeting hosted the largest gathering of members of the bleeding disorders community in the State of Indiana! The Meeting started off Saturday morning with a two part key note session. The first part was "It Takes a Village" presented by several key staff members including Jennifer Maahs, Brittany Savage, Don Molter, Cara Hannemann, and Carrie Starnes from the Indiana Hemophilia & Thrombosis Center. The presentation included important information about the many different services offered by the IHTC that are designed to partner with families and patients as they deal with the challenges of living with a bleeding disorder. The second part presented by Michelle Rice, Sr. Vice President NHF focused on the subject of today's healthcare headlines. Attendees learned valuable information on the importance of understanding their health insurance coverage, who to call when they have a question, how best to reach these individuals, and what information they need to provide. Saturday afternoon consisted of several educational break out sessions that included topics on VWD, the changing landscape of Hemophilia and new technologies available, "Mythbusters", the emotional well being in the Hemophilia community, and many more! Saturday night included the 2017 Hemophilia of Indiana awards and the 2018 Judy Moore Scholarship recipients. This year, it was an honor to announce that the 2018 Judy Moore Scholarship program awarded a total of \$30,000 to the winners!

Award Winners:

2017 Distinguished Individual Volunteer of the Year: Zachary Crabtree 2017 Distinguished Business: Waypoint Global 2017 President's Award: Jeanne Sagar

2018 Judy Moore Scholarship Winners:

John Bontrager, Irivin Castillo, Sarah Phillips, Rebecca Hutsell, Mary Lang, Ralph Alter, Matthew Olovich, Joseph Lay, Evan Moore, Zachary Crabree

The weekend concluded Sunday morning a general session presented by Michelle Rice and Brendan Hayes, Government Relations Specials National Hemophilia Foundation. The presentation included the importance of personal advocacy through a variety of situational discussions. Also included were tips on advocating for your health at school, at your HTC, and throughout life in general. Holl has already begun planning for the 2019 Annual Meeting! More information to come!



The 2018 Unite for Bleeding Disorders Walk was held on Saturday, August 25th! Hemophilia of Indiana is excited and proud to announce that we reached our fundraising goal of \$60,000!!! A very special thank you to all of our hardworking captains, team members, and donors! The Top Fundraising Team Award went to Bleeding Hearts for Blake, Team Captain Carla Glodowski! Here were our top five fundraising teams:

- I. Bleeding Hearts for Blake
 - 2. Currey's Cane-anites
 - 3. Burns and Steele
- 4. The Von-Kuehl Warriors
 - 5. Team Greenwood

Hemophilia of Indiana is proud to announce that we 8 participants that became "Factor Club" members! The "Factor Club" members are individuals that individually raised over \$500.00. This year's members were Dave Currey, Carla Glodowski, Kasey Shade, Deja Sturdivant, Pat Kotylo, Maggie Glodowski, Connor Kuehl, and Dustin Page! Holl would also like to say a very special thank you to our Local and National Sponsors, Team Captains, participants, donors and volunteers!! Stay tuned for information and the date for the 2019 Unite for Bleeding Disorders Walk!





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Publication: PEN 2.18 Column: As I See It

Changing Your Life: Setting Goals

L.A. Aguayo and Chad White

I Motivational guru Tony Robbins says, "If you talk about it, it's a dream. If you envision it, it's possible. But if you schedule it, it's real!"

How do you make a dream become reality? When we set a goal, no matter what it is, we focus on achieving it 100%. Creating Hemolife, bodybuilding, a competition, whatever the goal may be. We start by setting the target. Next, we want to document it: tell people our plans. This creates accountability. We would feel terrible, and would lose credibility and self-respect, if we told everyone we were doing something and then quit. Documenting our goal makes us work that much harder at it, even on days when we don't feel up to it. We can reach our goal only by making ourselves vulnerable and accountable. So we show our journey toward our goal in the raw—on Facebook, Instagram, Snapchat as it unfolds. We want to let people know that we are no different than they are, and that they, too, can reach their goals. This also can help inspire others. Goals take work, long and hard work, 24/7! We must do whatever needs to be done.

A great way to get started on a goal is to ask the most influential people you know for help. Get a team together if you can, and work together on your goal.

One important aspect of goal setting is to constantly reset your goals. When you achieve one goal, make another! Don't be afraid to fail; if you do fail, then adjust your goal as you go along. Maybe aim a little lower to create some small wins, or change up your schedule. Remember, if you do the same thing you've always done, you'll get the same thing you've always gotten. If you're experiencing difficulties repeatedly, then stop, evaluate, and make big changes. Failure isn't an option with this mentality. It's like climbing a hill or mountain that you thought was too high. Goals are a nonstop journey. If the goal is big enough, there will always be adversity and setbacks. That's part of growing. Goals are not meant to be easy. Most people don't even take the first step because it seems too hard and the results aren't guaranteed.

If you're experiencing success, great! Now double up on whatever it is you are doing.

L.A. and Chad's Formula for Success!

- 1. Choose a goal (no matter how big).
- 2. Define why you want it (your purpose).
- 3. Define what your desired outcome will be.
- 4. Decide on a timetable, and schedule it.
- 5. Find influential people who have achieved what you want, and ask for advice.
- 6. Make a detailed plan to reach your goal, and write it down.
- 7. Tell people your goals, and document your journey.
- 8. Take massive action!
- 9. Don't be afraid of failure, and be ready to adjust along the way.

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Hemophilia is an obstacle, but not one that has the power to stop us. Our minds are stronger than that! Remember, the body can do anything the mind can convince it to do. If you have hemophilia, factor up regularly! Reaching a goal is worth it, and once you do, you'll be addicted to success. Nothing is more gratifying than setting a tough goal and achieving it. Make a solid plan on how to go through each step to the finish, and then knock off each step, one by one. Adversity along the way will create opportunity at the end.

PotentialActionImage: Action interval int

Here's a mental framework we use to achieve our bodybuilding goals.

We all start off with some type of potential. Each person will be on a different level, but the potential is there; you just need to tap into it. When you realize you have that potential, you can take an action toward achieving your goal. And with that action, you'll get results. When the results are positive, you'll create new belief in yourself about the possibilities of achieving your goal. This new belief in yourself will increase your level of potential in return, giving you the ability to take a *bigger* action next time. The bigger action you take will get you bigger results, and the bigger results will create even more belief in yourself!

What if the results are negative? Go back to the action you took, reevaluate it, and take a new action. Keep the cycle going! If you keep repeating this process, you'll discover you're capable of accomplishing incredible things, because once your belief increases, you begin to develop new vision, which will create new goals.

Being with Hemolife is a dream come true. Not by magic, but by setting goals, and by hard work. Our next big goal is to speak at the World Federation of Hemophilia Congress! We believe it. So we know it's within our reach.

L.A. Aguayo, 29, has severe hemophilia B and lives in St. Louis. He has four children and works for Heritage Biologics. He created Hemolife.org, a website for leaders with bleeding disorders who share their stories of adversity to inspire the hemophilia community. Hemolife's mission is to inspire and motivate people who are going through extreme adverse situations.

Chad White, 44, has hemophilia A and lives in Windsor, Ontario. He is married to Jocelyn, has four children, and works at Ford Motor Co. He's a member of the Hemolife team and Hemophilia Ontario Adult network.





The Indiana Hemophilia and Thrombosis Center has much to celebrate this year—our 20th. Our mission to achieve a future where those with bleeding and blood disorders flourish remains at the heart of what we do. We're so thankful to the patients and their loved ones who have become like family to us over the past two decades. Here's to many more successful and healthy years to come.

Indiana's only Center of Excellence in bleeding disorders

- Comprehensive clinics with our expert multidisciplinary team
- Integrated pharmacy program accessible 24/7
- Nationally renowned for the treatment of bleeding and clotting disorders
- First HTC to receive Medical Home certification (AAAHC)
- Free CME education and 24 hours, 7 days a week consultative services for providers throughout the state
- Outreach clinics across Indiana, education and training for families
- Research to advance care and provide savings to patients and families

For more info, call 317.871.0000 For our Pharmacy, call 317.829.7778 Visit us online at <u>www.ihtc.org</u>





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 \geq 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 bleeds¹

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).

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.

For additional safety information, 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-lífe pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. 3. Data on file.

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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?

You should 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 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.
- Are pregnant or planning to 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).

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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.shirecontent.com/PI/PDFs/ ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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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Come and get a healthy head start on your Thanksgiving Day feast by joining us for the Fit Livin' ThanksGivin' Day Run!

Thursday, November 22, 2018!

This run not only benefits you and your appetite, but also supports **Hemophilia of Indiana (HoII)**. Holl is a 501c3 non-profit organization, that **serves over 1,400 Indiana patients and families affected by hemophilia and other bleeding disorders**. Proceeds from the event will support Holl's vital programs and services. Gather your family, friends, and come get some exercise and support a great cause! Each registered runner or walker will receive a finishing medal!

• Race location: Start/Finish at <u>Dillon Park</u> (146th and Hazel Dell behind Kroger) and scenic course through the beautiful **Lochaven** neighborhood.



• 4 Mile Run/Walk at 9:00am

\$35.00 Registration (through 10/29) \$40.00 Onsite Registration November 11/21

· Kids 200 Yard Fun Run at 8:45am

» Free Registration (through 11/21)
 *Kid's Race: Every child will receive a medal for participating.

NEW TO THIS YEAR 10TH ANNIVERSARY SWEATSHIRTS!!!

Awards: 1st, 2nd, & 3rd place male/female Costume Prizes: 1st male/female - Turkey/Pilgrim/ Indian

Pumpkin Prizes: There will be 10 pumpkins throughout the course. Whoever carries a pumpkin over the finish line will receive a prize.

More info: www.hoii.org/events/#thxrun

The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

Genentech Hemophilia A

GenentechHemophilia.com

Let's put science to work

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Upcoming Educational Dinners:

Contact Angel Couch at acouch@hoii.org to register. Check out our Facebook (@HEMOINDY) page and website for details on educational dinners!

Warsaw:

- **Topic:** Spanish Hello Talk: "Pasos Para Manejar Los Cuidados De Tu Salud De Forma Independiente
- When: Saturday, October 6th
- Time: 11:00am
- Where: The Vic at One Ten I 10 North Buffalo Street Warsaw, IN 46580

Indianapolis:

Topic:"Growing Through Life's Changes"When:Thursday, November 8thTime:6:00pmWhere:Location TBD

Future Educational Dinner Dates - Details Coming Soon!

October - CSL Educational Program Date and Time TBD



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