

In memory of Judy Kauffman

Elizabeth Seaton Schauermann

Judy Kauffman was a great woman who influenced countless lives. Without her, the road ahead will be tough for many of us. She was a rock within the bleeding disorder community for over 25 years,

from her start at Children's Hospital of Orange County in 1997 as a hematology/oncology nurse to Emory University in Atlanta as a hemophilia nurse coordinator. She later went on to Children's Healthcare of Atlanta working in pediatric hematology, and then became the nurse practitioner at Children's Mercy Hospital in Kansas City. Judy took a new avenue as a clinical support specialist at Bayer HealthCare before returning to her roots to finish her career at UC Davis as their hemophilia nurse coordinator.

Judy leaves behind her adoring husband Bob, who she loved so very much, her beautiful daughters Gina, Kimberly and Dana and her loving son Michael. She also leaves her sister Connie, who she greatly admired, her beautiful grandchildren, who she doted upon with joy, and her sweet dog Theo, alongside countless friends and dear colleagues she held near.

Judy had a strong love for the Lord and lived her life accordingly. She made God present in her daily life and shared her faith openly. She used to put sticky notes all over her car with Bible verses for inspiration. She had a dedicated chair in her office where she quietly did her devotions every morning before heading off for the day. One thing that brings so many of us comfort by her passing is that she is now rejoicing with her father in heaven, joined by her brother Bill who she missed so much while here on this earth.

Judy was a trusted friend and confidant. She made her friends feel special, loved and important. She made space in her busy life to make sure those she cared for knew how much they meant.

Judy's family was the light of her life. She always spoke of her grandbabies and the adventures she would take them on or the plans she had with them. She lived with joy for her whole family. She loved traveling with her husband and baking cookies during the holidays with her sister. Judy introduced many of us to her famous "Kansas City cherry chip cookies!" I know this year the holidays will hold a heaviness in many of our hearts.

Judy was a fierce advocate for her patients and the bleeding disorder community. She had been a lifeline for so many over the years. From helping moms with babies who were newly diagnosed with a bleeding disorder, to her adults that leaned on her kindness and expertise, Judy always made herself available to her patients, she cared for them deeply. She didn't just leave it all behind when the clock said 5 p.m., she worried and wanted to find solutions for those who needed help all hours of the day. She was called to be a nurse in this life, and she embodied everything that encompassed.

A heart of gold, a smile of pure joy, a kindness that extended to all she knew, that was Judy Kauffman. Thank you Judy for your love, friendship, strength and respect, and for serving our bleeding disorder community with passion and dedication. We will all be forever grateful. Until we meet again, rest in peace dear friend.



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AdvnovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.\!^2

*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

No actual patients depicted

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- <u>Children Under 12 Years</u>: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment?
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median[†] overall ABR[‡] of 2.0
 - $-\,$ 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

¹Median is defined as the middle number in a list of numbers arranged in numerical order.

*ABR=annualized bleed rate, the number of bleeds that occur over a year.

*Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE 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 mouse 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).

- Adolescents and Adults 12 Years and Older: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol⁵ patients) during 6 months on twice-weekly prophylaxis

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, diarrhea, rash, nausea, dizziness, and hives. 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. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. Haemophilia. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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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.

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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. diarrhea, rash, nausea, dizziness, and hives. 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-TAKEDA-7.

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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HFNC Board Member Randy Curtis is Recipient of NHF Award

Aug. 28, 2022

HOUSTON, TEXAS - Each year, the National Hemophilia Foundation (NHF) honors those who have made significant contributions to the inheritable blood and bleeding disorders (IBD) community at its annual Awards of Excellence program. Honorees are nominated by their peers for their outstanding dedication and service to the community. After careful deliberation, this year's winners have been selected and were announced at this year's Bleeding Disorders Conference (BDC) in Houston, Texas.

The Lifetime Achievement Award: Randy Curtis, Walnut Creek, CA;

Throughout his career in public health and industrial relations, Randy Curtis has worked tirelessly for the hemophilia community by collecting data and computing factor VIII for a multitude of organizations helping the IBD community. His contributions to the NHF MASAC Pain Group, the Hemophilia Utilization Group Studies, the Patient Reported Outcomes, Burdens and Experiences study, the Cost of Hemophilia Socioeconomic Survey, and many other initiatives are just some of many examples of the way Randy gives back to the community in which he belongs.



I have always tried to give back to the community, be it through my local chapter, legislative actions, or research. The fact that I love doing it is a bonus.

- Randy Curtis

Liz Schauermann **Bleeding Disorder Territory Manager**





Soleo Health is a local provider of complex specialty pharmacy and infusion services dedicated to the bleeding disorder community and the patients we serve.

Our Bleeding Disorder Therapy Management Program is led by specialized care teams with extensive experience in Hemophilia A, B, Factor X Deficiency, Von Willebrand, and other factor deficiencies. The bleeding disorders team provides individualized services and education, which encourages your independence and enhances your care experience.

Liz Schauermann devotes her full-time work in the community to better the lives of those with bleeding disorders.

Contact Liz Schauermann, Bleeding Disorder Territory Manager, to learn more or to submit a referral:

721 S. Glasgow Avenue, Suite C Inglewood, CA 90301

P: 866.665.1121 | F: 888.665.1141

C: 310.422.9621 | E: |seaton@soleohealth.com



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1155-C Arnold Drive, #236, Martinez, CA 94553 P: 510.658.3324 F: 510.658.3384 www.hemofoundation.org Creating
a Lifeline of
Community
and Support

Dear HFNC Community Member:

After yet another challenging year, we are just now beginning to be able to gather again and enjoy our community. Barring any unforeseen circumstances, we fully expect to be able to host Camp Hemotion in 2023 and need your help to ensure this program and our many others continue.

We are asking you to consider a contribution to the Hemophilia Foundation of Northern California to support our work. We have included an envelope in this edition of Infusions for that purpose. If your family has limited financial resources, you might consider the following suggestions:

- Ask people you know if they would consider making a gift to the
 organization during this season of holiday giving. Let people know that
 any gift of any size is both appreciated and goes directly to help
 families and children.
- Donate to Unite for Bleeding Disorders Walk! Ask at least two additional people to match your donation. YOUR donations provide critical services.
- Check with your employer (or with family and friends) to see if their company has a matching gift program. 90% of employees do not use their full matching gift amounts.
- Make a special contribution to honor a loved one.

Please consider HFNC in your giving plans this year so that we may continue our work supporting families and kids affected by bleeding disorders. Please use the enclosed envelope or our website to make your personal contribution.

With warm regards,

Dawn Pollard HFNC Board Director

Dawn Pollard

Andrea Orozco
HFNC Executive Director

**HFNC is a 501(c)3 organization and our Federal Tax ID No. is 94-1638703

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Ways to Give

GIVE NOW



DONATION OPTIONS

There are so many ways to support children, patients and families with bleeding disorders in Northern California! Your support and involvement empowers Hemophilia Foundation of Northern California to achieve our mission to provide a lifeline of support.

DONATE ONLINE

www.hemofoundation.org/support/donate/html

DONATE BY PHONE

510-658-3324

9AM-5PM Mon-Fri

DONATE BY MAIL

Hemophilia Foundation of Northern California 1155-C Arnold Drive #236 Martinez CA 94553

GIVING OPTIONS



















On Monday, October 24, 70+ golfers joined HFNC staff, volunteers and board members at the Jack Nicklaus designed golf course at Ruby Hill in Pleasanton to support our local bleeding disorders community. It turned out to be a gorgeous day, perfect to play 18 holes of golf with special incentive holes sprinkled throughout. After checking in at Registration, the golfers fueled up on juice, coffee and pastries before heading out to the Putting Green to get in some practice before the Putting Contest began. After being welcomed and thanked by Tournament Committee Chair, Pete Barbounis, the Ruby Hill Golf Course pro, Nigel, read everyone the course rules and sent them on their way to their assigned hole for the "Shotgun Start".

The biggest and best surprise for the golfers this year on the course, was the fun on Hole 18, where a "Ball Cannon" was set up where the golfers teed off. For golfers who purchased the chance, they could load a golf ball into the cannon and direct it as it got launched up to 450 yards down the course! That's quite a long drive by anyone's standards!

Players and volunteers enjoyed HFNC Board Member Pete's homemade sausage and pepper lunch or pizza, as well as refreshments donated by Pete and Jeff Bailey.

In the evening, the golfers and other guests enjoyed a sitdown dinner, including wine donated from the Meyer Family Cellars as the next round of fun began. After a heartfelt speech from one of our summer camp directors, Ben Martin, the Camp Hemotion Appeal started with the winner receiving a Magnum of champagne. Camp Hemotion is HFNC's summer camp for children in the bleeding disorders community and their siblings and we're so excited to have it returning in June 2023. We also had an auction of several vacation home getaways, with many participants vying for the chance to stay at Incline Village, Arnold and Hawaii. The winners of the drawings for San Francisco 49er suite tickets, Golden State Warrior 6th row tickets, Oakland A's tickets, Oakland Roots soccer tickets and a Ruby Hill Foursome were also announced, as well as winners of smaller items donated from community members and others. Our players couldn't rave enough about how gorgeous the course at Ruby Hill is and how much fun they had. The total raised for HFNC is still being tabulated, but we know that this event was a success!





The Scarpelli Charitable Foundation Mr. Michael Scarpelli and Ms. Janet Scarpelli











Christmas Riddles

Be The First To Match The Riddle To The Correct Answer.

A. Claus-trophobic

B. Santa Paws

C. It was feeling

D. Merry Xmas,

Deer! E. Crisp Kringle

crummy.

F. Santa walking

backwards.

G. Saint Nickel-less

H. At Snow-balls

J. A cookie sheet

K. Low 'elf-esteem

M. Fleece Navidad

N. An ice-burger

O. A Christmas

Q. Santa Clues

R. Jungle Bells

quacker

P. It's Christmas,

I. The elf-abet

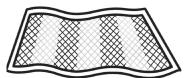
L. Silent Night

- What do you get if you cross Santa with a
- What Christmas Carol is a favorite of parents?
- What do you get if you cross Santa with a duck?
- What do monkeys sing at Christmas?
- What kind of people are afraid of Santa Claus?
- What did Santa change his name to after sliding down a chimney where the fire was still burning?
- What do you call Santa when he has no money?
- Why did the Christmas cookie go to the doctor?
- Where do Snow-Women like to dance?
- What is a snowman's favorite lunch?
 - What did the Gingerbread Man put on his bed?
- How do sheep say Merry Christmas in Mexico?
- What did the buck say to the doe on Xmas Day?
- Why was Santa's elf depressed?
- What goes Oh! Oh! Oh!
- What did Adam say the day before Christmas?
- What do elves learn in school?
 - Who delivers Christmas presents to dogs?

TOTAL CORRECT ANSWERS

Let's Learn About Kwanzaa

Below are 8 items found during the celebration of Kwanzaa. Learn about each item and then have fun coloring them in!



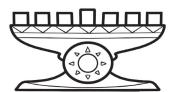
Mkeka A straw mat that holds the unity cup, ears of corn, fruit, and the kinara.



of Kwanzaa. There are 3 red candles, 3 green candles, and 1 black candle.t



Mazao Fruits, nuts, and vegetables placed on the mkeka, represent sharing, unity, and hard work.



Kinara A candelabra that holds 7 candles, one for each day of Kwanzaa.



Unity Cup or Kikombe A symbol of unity which is the base of all Kwanzaa principles.



Ears of corn One ear of corn is placed under the . linara to symbolize each child in the family.

Zawadi Gifts exchanged ith family members to celebrate the last day of

Woven tablecloths A commonly made craft exchanged on the last day of Kwanzaa.



Find the ten differences between the two pictures.











CALENDAR

DECEMBER			HFNC	Hemophilia Foundation of Northern California
12/1/22	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA		https://www.hemofoundation.org/
12/4/22	WinterFest	Mezcal Restaurant	AFFILIA.	TED ORGANIZATIONS
		San Jose CA	NHF	National Hemophilia Foundation
12/10/22	WinterFest	Nielsen Conference Center,	,	https://www.hemophilia.org/ NHF Chapters (See full list at NHF):
12/24/22	Christman Day (Observed)	Fresno	HFSC	Hemophilia Foundation of Southern California
12/26/22	Christmas Day (Observed)	Holiday HFNC closed		http://www.hemosocal.org/
12/26/22-12/30/22	HFNC Office Closed	Holiday HFNC closed	HASDC	Hemophilia Association of San Diego County
JANUARY				http://hasdc.org/
1/1/23	New Year's Day	Holiday HFNC closed	CCHF	Central California Hemophilia Foundation
1/2/23	New Year's Day	Holiday HFNC closed	АНА	https://www.cchfsac.org/ Arizona Hemophilia Association
	HFNC Holiday	,	Alla	https://www.arizonahemophilia.org/
1/5/23-1/8/23	NAACHO	Arizona	HFO	Hemophilia Foundation of Oregon
1/7/23	HFNC Annual Meeting	OakStop, Oakland CA		http://hemophiliaoregon.org/
., . , 23	& Board Meeting	z zocop, o s.maria o n	HFA	Hemophilia Federation of America
1/16/23	MLK Jr Day	Holiday HFNC closed		http://www.hemophiliafed.org/
			НСС	Hemophilia Council of California https://www.hemophiliaca.org/
FEBRUARY			WFH	World Federation of Hemophilia
2/8/23	Board Meeting	Virtual		https://www.wfh.org/
2/9/23-2/12/23	YETI Conference	Camp Collins, OR		
2/17/23-2/19/23	The Female Factor	Walker Creek Ranch	HEMOP	HILIA TREATMENT CENTERS HTC's
	Retreat	Petaluma CA		Hemophilia Treatment Centers:
2/20/23	President's Day	Holiday HFNC closed		Stanford University Medical Center https://www.stanfordchildrens.org/en/service/hematolog
2/28/23	Rare Disease Day	TBD		University of California at Davis
MARCH				https://www.ucdmc.ucdavis.edu/hemophilia/
TBD	HCC Health Summit	TBD		University of California San Francisco
3/1/23-3/31/23	Bleeding Disorders	YOUR City		https://www.ucsfhealth.org/clinics/hemophiliatreatment_cent
3/1/23-3/31/23	Awareness Month	TOOK City		UCSF Benioff Children's Hospital Oakland https://www.childrenshospitaloakland.org
3/8/23	Board Meeting	Virtual/Tentative		Valley Children's Hospital
	NHF Washington Days	Washington DC		https://www.valleychildrens.org/
3/10/23-3/12/23	Family Camp	The Taylor Family Foundation	on.	
	, y I	Camp Arroyo, Livermore, C		
3/19/23-3/21/23	Future Leaders Program HCC	Sacramento CA		
3/21/23	LEG Day	Sacramento CA		
APRIL				
4/9/23	Easter	Holiday HFNC closed		
4/11/23	Board Meeting	Virtual		
4/13/23-4/16/23	Hemophilia Federation of America Annual Symposium	Orlando, FL		
4/23/23	World Hemophilia Day/ Asian Infusion	TBD		
4/28/23-4/30/23	Western States Region IX Conference	Manhattan Beach, CA		



FOR ALL BLEEDING DISORDERS

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PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with members' names, addresses or any other personal details. Paid advertisements and paid inserts should not be interpreted as a recommendation from HFNC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements or paid inserts.

Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

Information and opinions expressed in this publication are not necessarily, those of the Hemophilia Foundation of Northern California, or those of the editorial staff.

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