FALL 2022

Infusions

INDIVIDUALIZED EDUCATION PLANS EXPLAINED

IEP – INDIVIDUALIZED EDUCATION PROGRAM (IEP)

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA) IS A FEDERAL LAW THAT IDENTIFIES CHILDREN WITH DISABILITIES AND PROVIDES THEM WITH SPECIALIZED PROGRAMS AND SERVICES TO HELP THEM SUCCEED IN SCHOOL. THE PROCESS TO GET YOUR CHILD THE SERVICES HE OR SHE NEEDS IS CALLED THE INDIVIDUALIZED EDUCATION PROGRAM (IEP) PROCESS. THE TERM IEP DESCRIBES BOTH A MEETING AND A WRITTEN DESCRIPTION OF YOUR CHILD'S PROGRAM.

Who is eligible?

- ADD (Attention Deficit Disorder)
- ADHD (Attention Deficit Hyperactivity Disorder)
- Autism
- Hearing impairment (including deafness)
- Mental retardation
- Multiple disabilities
- Orthopedic impairment caused by congenital anomalies
- Orthopedic impairments caused by diseases
- Orthopedic impairments – other
- Other health impairment (OHI)
- Other medical impairments
- Speech or language impairment
- Visual impairment (including blindness)
- Serious emotional disturbance
- Specific learning disability
- Traumatic brain injury

Important Information

IDEA says that in order for a child to qualify for special education, the student's impairment must negatively affect his/her educational performance and require special education. *In other words, the child's disability is causing him/her to have difficulty in school.*

Your child has the right to an initial evaluation (assessment), with further evaluations every three years. If you are not satisfied with the initial evaluation or you feel that your child's disability or education needs have changed, you may request more frequent assessments.

Who attends this meeting?

- General education teacher
- Parent
- Qualified district representative, e.g. program specialist, psychologist, someone who can make financial decisions
- Special education teacher
- Someone who can discuss testing results

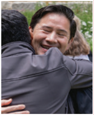
What is the parents' role?

- Attend the IEP
- Give information that will be helpful about your child and how they act and learn
- Ask questions
- Participate in decisions
- Bring along another person or advocate who knows your child

Questions to ask and answer at the IEP meeting

1. What special education services will they receive? e.g. Special Day Class (SDC), Resource Specialist Program (RSP)
2. What related services will they receive? e.g. Speech & Language, Occupational Therapy, Adaptive Physical Education
3. What extra help, people or materials will they receive?
4. What will program modifications look like? e.g. extra time, copies of notes, shorter assignments
5. Who will help support and advise the school personnel?
6. What support and services are needed for the student to be involved in nonacademic activities? e.g. physical education, library time, assembly time

IN THIS ISSUE



HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA ONLINE EDITION

Continued from Page 1

504's, Individualized Health Care Plans and Home + Hospital Instruction Explained

504 Plan

Section 504 of the Rehabilitation Act of 1973 protects the rights of people who have handicaps in programs that receive money from the Federal Government. Because public schools get federal funding, they are required by law to address the education of students with special needs.
For all 504 Education Plans, medical documentation of your child's disability is required. The plan is reviewed on a yearly basis and can be revisited any time if you or your Child's teacher asks.

Individual health care plan - Individualized health plans and emergency care plans provide information for school staff on how to manage a health condition or handle an emergency situation which may occur as a result of the student's health condition.

What disabilities are covered under section 504?
Has a mental or physical impairment which substantially limits one or more of such persons major life activities such as caring for oneself, walking, seeing, speaking, learning, performing manual tasks, hearing, breathing, or working. (Activities of daily living)
Has a record of such impairment; and
Is regarded as having such an impairment

What accommodations can be covered under a 504 plan?

- Each child's needs are determined individually. Deciding what needs are appropriate for your child is done by the school district depending on the nature of your child's condition. The goal is to give your child the same opportunities when compared to the non-disabled. Accommodations that may be used, but are not limited to, include:
- Flexible class schedule
- Modified testing arrangements
- Note-taker
- Audio recorder
- Extra time between classes
- Modified physical education program

How do you apply?
Parents requesting a 504 plan for their child must put that request in writing and give it to school personnel. The school will schedule a meeting with the parent, discuss the situation, and set up the plan. If your child has medical problems, ask for the school nurse to be included in the meeting. They can write an individual health plan to meet your child's medical needs.
If you disagree with the school's evaluation, you can request a due process hearing or file a complaint with the Office for Civil Rights. The school district is not required to pay for an outside independent evaluation.

Home/Hospital Instruction
The purpose of home and hospital instruction is to make sure that students with a temporary disability or illness continue to receive school instruction when they cannot attend school. This can take place in the home or hospital located within the school district.

1. Parents must write a letter to the district requesting a home/hospital teacher to be sent to their home. Within 5 days of receiving this letter the school district must decide whether or not a teacher is needed. Teaching should begin no later than 5 days after approval of the letter.
2. A school teacher will be sent to the home, hospital or mutually agreed upon place to meet with the student. Each school district must provide 5 hours of home/hospital teaching per week until the student can return to school. An adult must be present when the teacher is there.
3. The goal of home and hospital instruction is to make sure the student keeps up at the level of performance they were working at before becoming disabled. This is to make sure that students can successfully resume school with their peers when they are physically able.

Home and Hospital Instruction is written into the California Education Code, EC Section 48208 and 48206.3.

How do your social workers help?
Social workers will conduct a psychosocial assessment to determine needs. This will vary from family to family.
They can attend meetings with your student and you and assist in advocating in real time as concerns arise.
Meetings can be attended in person or via phone/Zoom etc.

Thank you to Michelle Wright, MSW
UCSF Pediatric HTC
for permission to reproduce this article

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At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

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GENENTECH IN HEMOPHILIA

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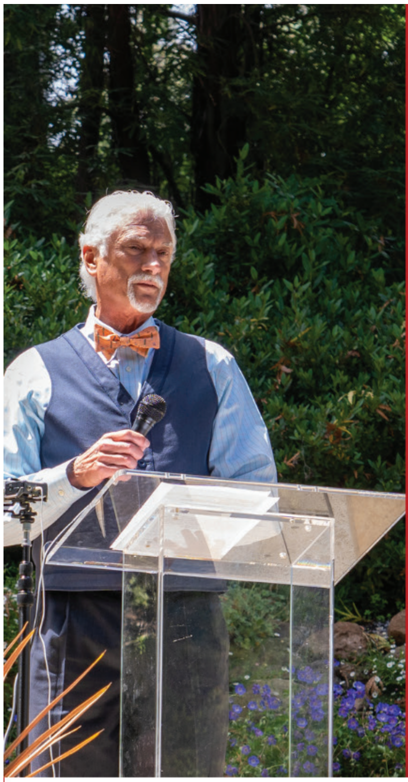

VAL BIAS

Celebration of Life

2022

Hemophilia Memorial Circle
AIDS Memorial Grove
San Francisco Golden Gate Park



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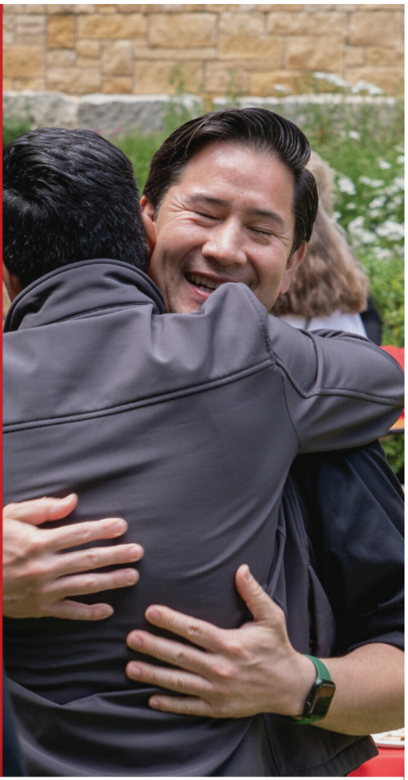
2022

Hemophilia Memorial Circle
AIDS Memorial Grove
San Francisco Golden Gate Park







VAL BIAS

Celebration of Life

2022

Hemophilia Memorial Circle
AIDS Memorial Grove
San Francisco Golden Gate Park



The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

COOK ALONG WITH CHEF HAKEEM!

ASIAN INFUSION

INVITES

YOU!

8 SEPTEMBER 2022

6:30PM PT

ZOOM

MENU

Pork Ginger Potstickers

Vegetable Vermicelli

REGISTER

hemofoundation.org/events

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]
REAL LIFE. REAL BLEED PROTECTION.*

AdynovateRealLife.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.[1,2]

*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 bleeds[2]

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]

- **Children Under 12 Years**: 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[2]
  - 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
- **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 groups[2]
  - 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-protocol[§] patients) during 6 months on twice-weekly prophylaxis

[†] Median 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).

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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US-ADY-0351v1.0 08/21

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?

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 breast-feeding 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.
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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 Staff Spotlight: My Hemophilia A Story

by Ashley Gregory

Anthony and Nicholas were born in 1998. I had no family history of bleeding disorders and now had twins with severe hemophilia A. As you can imagine, I became informed about their condition and kept in contact with the treatment center as they grew. It was that year that Project Red Flag was launched and I remember being curious because I had puzzling symptoms over my life. But life would take a darker turn and it would be a long time before I would revisit this topic.

One day Anthony didn't seem right, he was lethargic and not eating. I took him to our pediatrician who suspected flu. I remember looking directly at her and saying shouldn't we infuse him since his head is hot but he has no fever? She said no, take him home. I ended up taking him to the ER where we learned he had a brain bleed. Despite heroic surgical efforts, and finally some factor, he died the next morning. He was 11 months old. This began a slow tumble into despair that our family would not emerge from until the next decade.

During this time, unbeknownst to me, researchers were learning that women with the hemophilia gene exhibit unexplained bleeding symptoms and need treatment. Some doctors successfully began working with women to determine how to manage symptoms using factor. Some doctors were learning that despite factor levels, women who were experiencing unexplained bleeding responded well to treatment with factor.

It was this unexplained bleeding that pulled me back into my own search for a diagnosis. While volunteering at my local foundation, I would hear rooms full of women that were continuously citing similar untreated symptoms around unexplained bleeding. I began to realize there was a community problem. Women in our community, like me, were experiencing unexplained bleeding that was not being addressed despite reporting to their doctors. It was usually explained away as 'sometimes these things happen' or 'all the women in this family are like this, deal with it'

This led to a personal diagnostic journey to seek a diagnosis and treatment as well as a career in advocacy and education in bleeding disorders. I began attending local, regional and national programs that provided excellent education about my bleeding disorder as a woman and brought me in contact with treaters who were successfully treating women's unexplained bleeding in their clinics using all the medications available to men with bleeding disorders. This led to an even greater understanding of my particular bleeding disorder as a woman with two x chromosomes. I learned that lyonization can cause an effective x to stop working and an ineffective x to take over and produce blood with lower factor levels. Thanks to Dr. Barbara Konkle, and the My Life/Our Future research, I learned that some mutations (mine and my son's) can present a high factor level, but bleed like a severe! I finally learned that connective tissue disorders can be present in persons with bleeding disorders and this can exacerbate bleeding.

Continued on Page 11

MY STORY *Continued from Page 10*

Prepared with this knowledge, I humbly entered the HTC near me so well known for treating those like my son. I presented the collective knowledge I had gathered, my symptoms and my history. I trusted I would be heard and cared for. I brought my mother who had been by my side through all of my pain. I could not have been more wrong. The treatment center told me my levels are too high for my swollen ankles and knees to be caused by hemophilia and my petechiae were birthmarks. My unexplained bleeding history was useless in gaining a diagnosis here. I was also seen by genetics who told me I lacked enough markers on the list to have a connective tissue disorder. I was left with the option to do nothing or to have a synovectomy on my right ankle to see what the fluid in it was. I knew that without factor coverage that could be a long time healing based on my past so I politely thanked them and declined.

I decided it was time to embark on a new thing, medical tourism, so I could visit one of the treaters I had met at a national symposium. I crossed state lines and in a different state than the one I reside, I saw an expert and was given a thorough medical evaluation, history review of symptoms, physical evaluation and lab workup and diagnosed with hemophilia A (symptomatic carrier) and hypermobility syndrome, a connective tissue disorder. I was prescribed Amicar for mucosal bleeding and factor for muscle or joint bleeding. An emergency medical card was prepared for me with my treaters name, contact number and my diagnosis. A medical alert bracelet was ordered for me. I was instructed to contact the treatment center and treat on demand as needed. I did exactly that and was surprised to find that when I treated a bleed, my entire body felt better; things that had hurt my entire life had stopped hurting; my petechiae cleared up and the swelling in my knees and ankles would subside. Then it would all return as the factor would leave my body and I would be in pain again. I was able to access treatment from that HTC out of state for a short time and I was empowered to treat my hemophilia the same way I was empowered as a young mother to treat my son Nicholas' hemophilia when he was growing up. Since I had been infusing him for years, I infused myself easily and kept a log of bleeds and treatments. I saw improvement of my energy level and ability to endure when I was using factor.

But I am now no longer able to do so. You see, our state system that pays for factor for persons with bleeding disorders requires a doctor in our state to write the prescription. In the past and through my out of state HTC, I was able to access free trials of factor products and those have run out. So far, I have not found a doctor in my state knowledgeable about my particular genetic mutation that causes me to have a high factor level and bleed severely. So I have no access to factor any more. I am now a woman without a treatment center and without treatment. I am in pain and I suffer, as does my family, each day I am not living my best life.

However, I am grateful to my experiences, to my sons that were born with hemophilia and to Anthony who didn't survive the lack of knowledge that prevails to this very day and prevents his mother from treatment and medication. I am grateful to Nicholas who bears witness to the stark contrast in gender care in hemophilia. I have built a career advocating for those like me that are unable to access the care that we know is needed. I am grateful for all of these experiences but I would also like to be grateful for access to treatment for my hemophilia. It is my hope this will be a reality soon.

A list of my symptoms over my life:

(just the highlights, there's so much more...)

- At the age of four was my first symptom memory; watching Snow White in a Palo Alto theater, it was 1969 and all I could do was cry because my knees hurt so much. My parents had no idea why and I had no words to describe the pain and so it went unattended to.

- At the age of nine, we moved to Santa Cruz where I had to traverse woodsy mountains to reach my school bus stop daily. Once again, I encountered pain that brought tears and immobility and this time I was diagnosed with pre patellar chondromalacia. I was instructed to avoid hills and stairs, rest, ice and elevate; a futile instruction as my bedroom was up a flight of stairs and there is the aforementioned school bus stop. I lived in pain that kept me sedentary until, by chance, we moved to a single level home in a flat neighborhood.

- At the age of 10 I started my period. I would pass heavy jelly clots, experience extreme pain, get bruises under my eyes (my mom could tell I was on my cycle from this symptom) and become anemic, exhausted and unable to attend school or enjoy activities. I would soak through protection and ruin sheets. At school during my period, I was in the bathroom more than I was in my classroom due to leakage management. Treatment for this would never come and I spent my menstruating years suffering the effects of anemia.

- At the age of 15 I injured my ankle by slicing open my skin on a wooden board during a routine jump over some rocks and mud in a backyard. The wood was jagged and uneven. My leg took an entire year to heal from that cut. It kept reopening and oozing.

Continued on Page 12

MY STORY *Continued from Page 11*

- At the age of 16 I held a job at McDonalds', working long shifts standing on a brick floor. My knees and ankles had become swollen permanently by then and I was in constant pain and fatigue. At school during the day, I would draw my legs up under my body to prevent my ankles from dangling as the pain was unbearable. These were the days before ride apps and I would sometimes call my puzzled friends to give me a ride home when the walk was too much for me. I had no idea why I was so tired and hurting all the time.

By the time I became sexually active, I learned that I bled with intercourse regardless of my cycle.

- At the age of 21 I was diagnosed with gout (red herring) in my big toe. I now recognize this was a bleed.

- At the age of 25 I became pregnant with my first child and experienced anemia, second trimester spotting, petechial hemorrhaging around my face during pushing and unexplained, prolonged bleeding postpartum. My next child would bring more anemia, second trimester spotting, a throbbing pain behind my left eye leading to a spinal tap that unexplainably would not clot causing a weeklong leak in cerebrospinal fluid, petechial hemorrhaging of my face again and unexplained prolonged postpartum bleeding. My third child would bring more anemia, petechial hemorrhaging and unexplained prolonged postpartum bleeding with unexplained prolonged incision healing time. None of my first three children have a bleeding disorder although all of my children have a connective tissue disorder

- At the age of 27 my wisdom tooth extractions bled inexplicably for weeks.

- At the age of 28 I took myself to the ER with unexplained excruciating knee pain. I was told there was nothing to be done and was sent home.

- At the age of 32 I gave birth via cesarean section to Anthony & Nicholas, twins with severe hemophilia A. I bled jelly clots from the c-section and bruised profusely at the site of the incision, into my groin and down my legs. I experienced a bleed in the incision that was a pain unlike any other, like white hot fire dipped in bleach being stabbed in my gut.

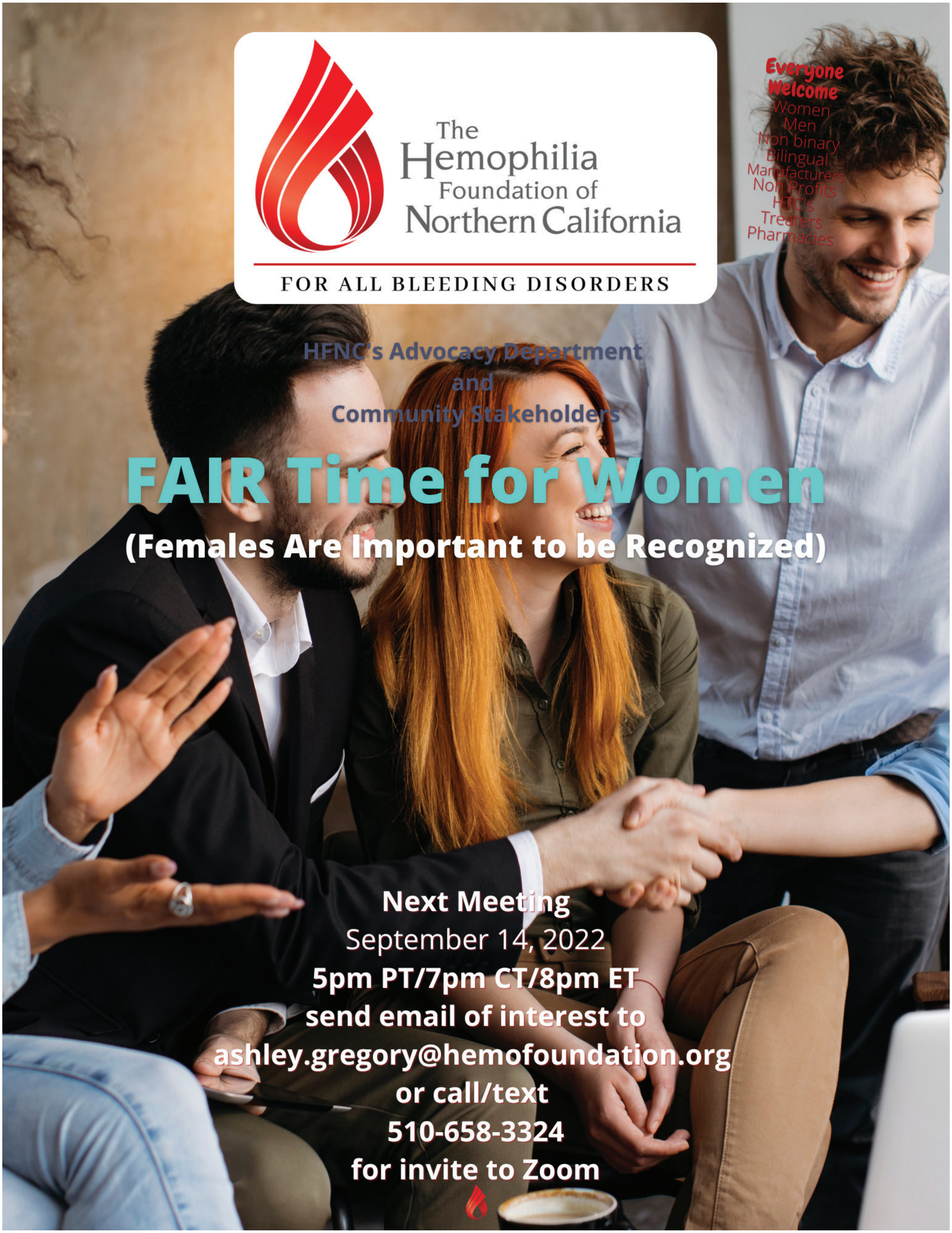
- At the age of 35 I was diagnosed with fibromyalgia (red herring).

- At the age of 45 I was diagnosed with tendonosis (connective tissue disorder related)

- At the age of 53 I was diagnosed with hemophilia A (symptomatic carrier) and connective tissue disorder and prescribed Amicar, factor and physical therapy for my connective tissue disorder.

- At the age of 56 I ran out of free factor trials and now have no access to the medicine that helps me be able to function because the state I live in does not recognize my diagnosis.

I am hopeful though due to FAIR Time for Women, a national grassroots coalition that has formed under HFNC's Advocacy Department and is bringing together stakeholders in bleeding disorders to overcome access to diagnosis, treatment and medication for women. Blood brothers have risen up to support their blood sisters in this unified call for action. As we have seen in our collective community past, we can achieve anything we set our mind to, like securing the nation's clean blood supply or ensuring access to life saving HIV and Hepatitis C medication. With manufacturers, specialty pharmacies and HTC's, we can all work together to make this change come about. The future is female. The future is FAIR.



The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

Everyone Welcome
Women
Men
Non binary
Bilingual
Manufacturers
Non Profits
HTC's
Treaters
Pharmacies

HFNC's Advocacy Department
and
Community Stakeholders

FAIR Time for Women

(Females Are Important to be Recognized)

Next Meeting
September 14, 2022
5pm PT/7pm CT/8pm ET
send email of interest to
ashley.gregory@hemofoundation.org
or call/text
510-658-3324
for invite to Zoom

CSL Behring
Biotherapies for Life™

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

10/1

5-8pm

GOLF COMMUNITY EDUCATION

JOIN US!

Top Golf Bays
Education
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SPEAKER: PETE D
PATIENT ADVOCATE AND GETTIN' IN THE GAME ATHLETE

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95002

REGISTER HEMOFOUNDATION.ORG/EVENTS

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

Family (day) Camp

10am-3pm PDT

October 15

5535 Arroyo Road
Livermore CA 94550

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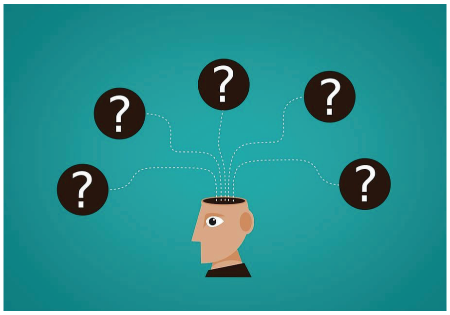
BAY AREA CHILDREN'S THEATRE

Register hemofoundation.org/events

What kind of insurance do I need to have to get into the LPCH Hemophilia Treatment Center?



By a Community Parent

Q: Is Stanford Children's Health part of your insurance plan's network (=in-network)?

A: Your insurance provider may ask you for Stanford Children's Health's group NPI or Tax ID to look up in their system whether you are in-network or out-of-network. Your physicians and hospital each have an NPI and Tax ID number:

- Stanford Children's Health Physicians Group NPI: 1417907940
- Stanford Children's Health Physicians Tax ID: 26-0089066
- Lucile Packard Children's Hospital Stanford NPI: 1467442749
- Lucile Packard Children's Hospital Stanford Tax ID: 77-0003859

NPI & Tax ID #s
In general the Physicians Group NPI and Tax ID are needed for outpatient visits and the Hospital NPI and Tax ID are needed for inpatient stays. However, some circumstances dictate using both.
It is therefore highly recommended to confirm with your insurance that both the Physicians Group and the Hospital Tax ID/NPI are in-network. Below is the link to Stanford's LPCH - w/ NPI & Tax ID #s
Insurance Information - Patients & Visitors - Stanford Children's Health
https://www.stanfordchildrens.org/en/patient-family-resources/insurance-information#toppick
Go to: Insurance Information - Patients & Visitors -Stanford Children's Health Insurance Information featuring Employer Group Plans, CalPERS, Tricare, Individual/Co…

KEY: All billing for the Hemophilia Treatment Center (HTC) falls under Lucille Packard Children's Hospital NOT Stanford Hospital. I spoke to Alma at the LPCH Financial Counseling Program - 650-736-2273. She walked me through the Stanford website to show me what health insurances LPCH works with the HTC. As of 2022, LPCH approves the following health insurances in Santa Clara County. If someone lives in a different county they need to look up their particular county to find the types of health insurances in their area.

Private Insurances: Individual and Covered California Plans - Stanford Children's Health
Individual and Covered California Plans - Stanford Children's Health
Santa Clara County Individual Plans:

- Covered California Blue Shield Silver 94 TRIO HMO
- Health Net PPO (get directly through a broker or Health Net)
- Santa Clara Medi-Cal plans:
  - Anthem Blue Cross Partnership Plan
    - (800) 407-4627
    - TTY/TDD (888) 757-6034
  - Santa Clara Family Health Plan
    - (800) 260-2055
    - TTY/TDD (800) 735-2929

*For Medi-Cal… In order to be seen at Stanford Children's Health, your Primary Care Physician must refer you and your medical group or health plan must authorize all services provided at Lucile Packard Children's Hospital Stanford or by Stanford Children's Health specialist physicians.

Name Lucile Packard Children's Hospital/Stanford Children's Health
Location 725 Welch Road Palo Alto CA 94304
Hours 24 hours on call; 8-5 M-F medical visits
Phone 650-497-8000 (Hospital Operator)
Social Services 650-497-8303

Liz Schauermann
Bleeding Disorder Territory Manager

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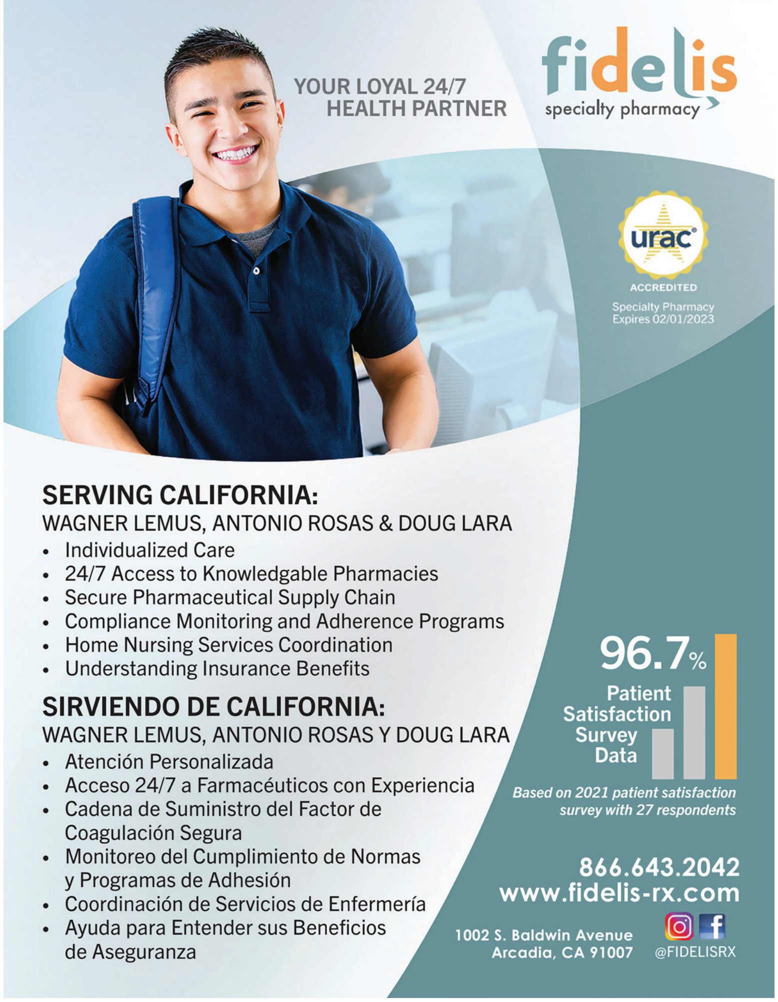
Liz Schauermann devotes her full-time work in the community to better the lives of those with bleeding disorders.

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: lseaton@soleohealth.com

www.soleohealth.com



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HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

CHARITY GOLF TOURNAMENT

2022

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

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MONDAY

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REGISTRATION : HEMOFOUNDATION.ORG/EVENTS

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

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HOUSE OF SAMBA KIDS

6 NOVEMBER 2022
9AM - 11:30AM

AT THE AMPHITHEATRE

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Register@ hemofoundation.org/events

12/4

Mezcal
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Save the Date

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

HFNC Winter Fest

- Come see Santa!
- Food Stations
- Games

Watch for registration to open at
hemofoundation.org/events

12/10

FRESNO

Save the Date

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

HFNC WinterFest

- Come see Santa!
- Lunch
- Games

Watch for registration to open at hemofoundation.org/events

Kid's Page

FALL WORD SEARCH

FALL

WORD SEARCH

C S C A R E C R O W I O P S R
R E E T I O E A D N S T I W E
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R E O O H U T P Q Q R U I T E
O M N L E A V E S U P N M E T
P B I W U V N E P I A R A R U
U E K R I M R K R L D O G I N
R R P O U H A Y S T A C K B T
E I M T P T I W U G F A M S S
B U U E A F E R S J I O E Q E
O A P F T U R K E Y B V R U H
T W R A S O I S C M R P I A C
C H I L L Y D P G A N W A N J
O A P L U Q K O H L J A E R G

ACORN
APPLE
AUTUMN
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HALLOWEEN
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FALL WORD SCRAMBLE

FALL

WORD SCRAMBLE

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ERBOMENV ____________________
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CUSENTHT ____________________
MANUTU ____________________
EHTVSAR ____________________
KTAECJ ____________________
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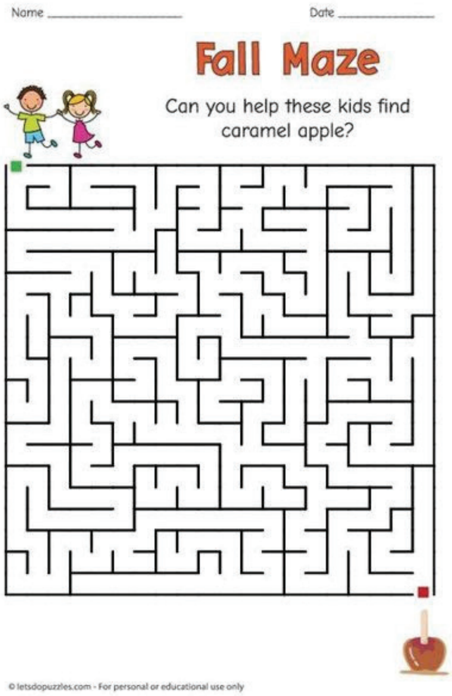

Name ____________________ Date ______________

Fall Maze

Can you help these kids find caramel apple?

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CONGRATULATIONS!!

2022 Scholarship Winners

Niko Fidler

Cal Poly Pomona

Niko Fidler's scholarship essay focused on how his hemophilia has shaped his life and helped him to move in the direction of wanting to study Kinesiology, as his essay excerpt shows:

"I plan to study Kinesiology, the mechanics of human movement and how they impact health and well being, with a long term goal of becoming a physical therapist.
I had a sports injury in 2019. Through working extensively with my physical therapist over several months I realized that it was an occupation I am interested in pursuing. When I looked into becoming a physical therapist and became aware of the kinesiology major I realized it provided a path to several fields within physical therapy. Immersing myself into a kinesiology program will bring clarity to my career aspirations, as well as a solid educational foundation to achieve a degree."
Later Niko wrote
"The versatility of this major makes it valuable from early childhood all the way through professional athletics and performance optimization.
Physical therapists face a variety of prominent challenges in today's society. At the head of these struggles is telehealth services, in which medical support is provided digitally over the phone or a zoom call without in person meeting. This is fundamentally problematic with physical therapists trained for physical interactions with clients. Telehealth as a strategy is controversial and still in development. In order for telehealth to be effective and efficient, further systems must be put into place."

Niko Fidler, Recipient of the DePauw Scholarship

Ramona Jalomo

California State University Monterey Bay

Ramona Jalomo wrote about the struggles her bleeding disorder made her face, particularly as a teen-ager, in this excerpt from her scholarship essay.

"I was often limited to what I did and was absent so much due to my bleeding disorder Von-Willebrands was quite a challenge because it was almost impossible to catch up with everyone else in my class. Studying psychology will allow me to speak out to others if they are going through a time where they feel indifferent to the rest such as | did. I can guide them on the path to making sure that they find themselves in this big world and strengthen them to take on the challenges that the future has to offer. Mental health is something that should always be prioritized no matter the age. Everyone is human and everyone experiences mundane emotions. They have every right to feel the complexity of being a human, a human that goes through the daily struggles of possibly just waking up for a brand new day. We always need that extra guide in our lives whether we admit it or not, we always seek that guidance so that we do not fall too far off the path of life."

Ramona Jalomo, Recipient of the Kurt Pollard Memorial Scholarship

GOOD LUCK IN YOUR FUTURES!

Apply for Scholarships in 2023 starting January 25

hemofoundation.org/scholarships

CONGRATULATIONS!!

2022 Scholarship Winners

Eliana Horowitz

College of the Redwoods

Eliana Horowitz's passionate essay started off immediately talking of her future plans, as this excerpt from her essay shows:

"I am looking forward to implementing my plan to attend College of the Redwoods to get certified as a medical assistant (CMA) and begin completing the courses necessary to get my Associate Degree in Nursing (with Registered Nurse) for transfer to a Bachelor of Science in Nursing (BSN) program at a four-year university. I plan to use the CMA certificate to obtain a job as a local medical assistant and work myself through college, debt-free. Not only will this provide a more stable income as a college student than working in fast food or retail, but it will also provide valuable experiences for potential careers.

This will (hopefully) only be the beginning for me. After obtaining my CMA, RN, and BSN, I plan to attend graduate school to get my Nurse Practitioner license and, ultimately, become a nurse anesthesiologist."

She goes on to talk about her interest in the medical field being strongly influenced by her own diagnosis of having a bleeding disorder and how she has been a volunteer for HFNC, HCC and NHF. We at HFNC truly wish Eliana much success at College of the Redwoods and in all of her future endeavors.

Eliana Horowitz

Mihir Joshi

UCSF

Mihir Joshi's essay started with him watching his own blood, as this excerpt showed:

"For once, the sight of my blood actually calmed me down. Watching it jump out into the hub of the needle and then disappear back into my arm as the familiar taste of saline came into my mouth meant that I had succeeded – I had infused my recombinant factor VIII."

Later as Mihir explained the experiences that had helped to define his life as someone living with hemophilia and what had led him to choose to enter the medical field (he was finishing his 4th year of medical school), he wrote this:

"As a physician, I hope my advocacy will help protect the child who cannot stop bleeding, serve those in under-privileged communities, and champion minority populations. It is through this advocacy, whether it is for the clinical pathway for a singular patient or the systematic review of policies and processes, that I intend to contribute to the recursive advancements of medicine."

Mihir Joshi

GOOD LUCK IN YOUR FUTURES!

Apply for Scholarships in 2023 starting January 25
hemofoundation.org/scholarships

sanofi

Connected.
Together.

For me, being a Community Relations and Education (CoRe) Manager for Sanofi is about empowering the hemophilia community by providing a personal connection to education and resources.

Cathy Marquez-Velasco
CoRe Manager for
Northern California, Nevada,
Hawaii & Guam

Stay connected.
530-228-5403
cathy.marquez@sanofi.com
RareBloodDisorders.com

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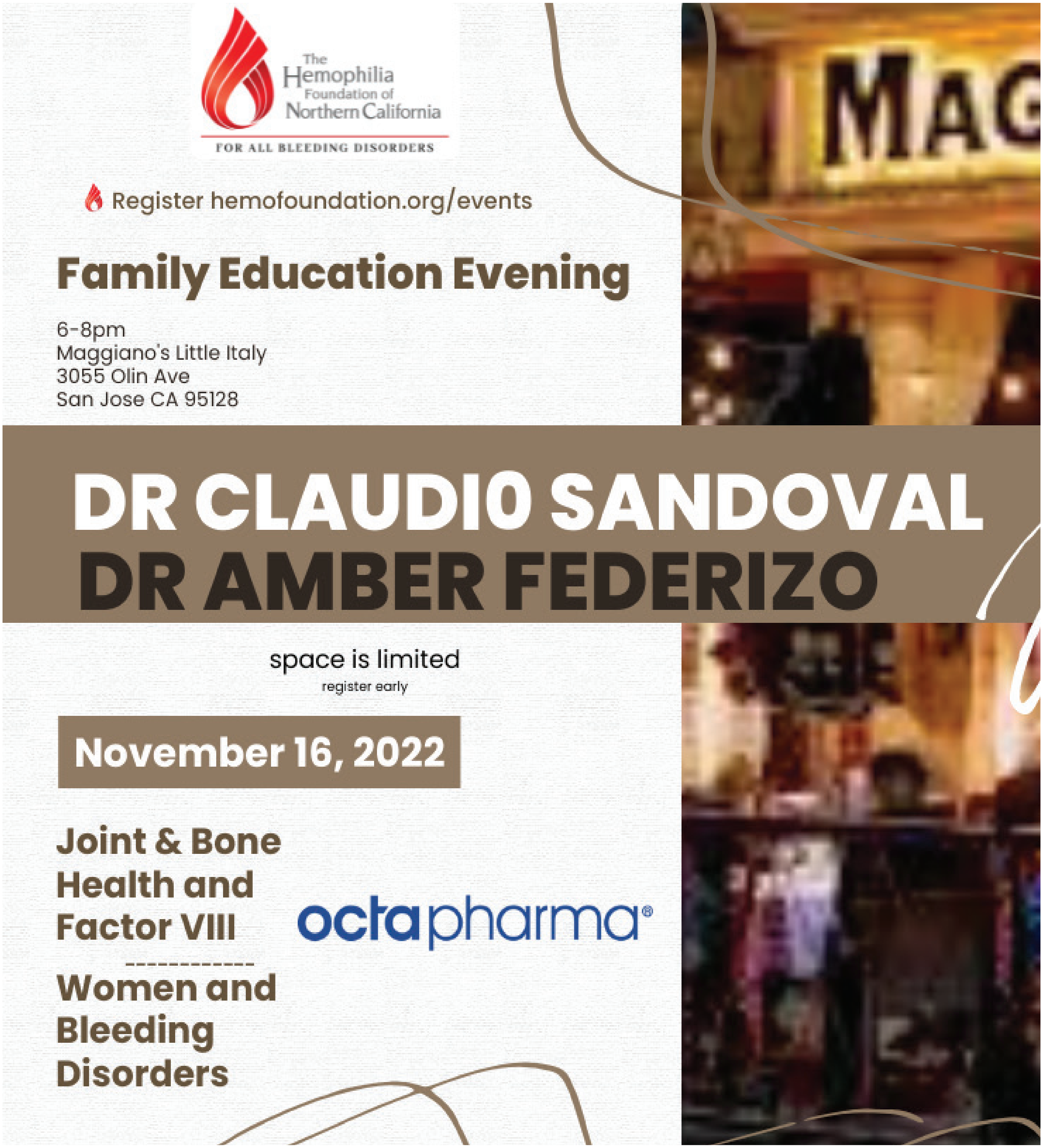

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

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space is limited
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November 16, 2022

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Women and Bleeding Disorders

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CALENDAR

SEPTEMBER

9/5/22	Labor Day	Holiday HFNC closed
9/8/22	Asian Infusion	Virtual
9/14/22	Bayer Walk Kickoff	Virtual
9/23/22-9/25/22	Familia de Sangre	Anaheim, CA

OCTOBER

10/1/222	Topgolf	Topgolf San Jose CA
10/15/22	Family Camp (in-person)	Camp Arroyo TTFF
10/15/22	NHF Red Tie Soiree	Julia Morgan Ballroom SF CA
10/24/22	Golf	Ruby Hill G.C. Pleasanton

NOVEMBER

11/6/22	Walk	Lake Merritt Amphitheatre, Oakland
11/8/22	Board Meeting	Virtual
11/14/22-11/17/22	NHF Chapter Leadership	Scottsdale, AZ
11/24/22-11/25/22	Thanksgiving Holiday	Holiday HFNC closed
11/29/22	Giving Tuesday	Campaign

DECEMBER

12/1/22	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/4/22	WinterFest	Mezcal San Jose CA
12/10/22	WinterFEST	Fresno
12/26/22	Christmas Day (Observed)	Holiday HFNC closed
12/26/22-12/30/22	HFNC Office Closed	Holiday HFNC closed

JANUARY

1/2/23	New Year's (Observed)	Holiday HFNC closed
1/8/2023	Annual Event	TBD

HFNC	Hemophilia Foundation of Northern California https://www.hemofoundation.org/

AFFILIATED ORGANIZATIONS

NHF	National Hemophilia Foundation https://www.hemophilia.org/ *NHF Chapters (See full list at NHF):*
HFSC	Hemophilia Foundation of Southern California http://www.hemosocal.org/
HASDC	Hemophilia Association of San Diego County http://hasdc.org/
CCHF	Central California Hemophilia Foundation https://www.cchfsac.org/
AHA	Arizona Hemophilia Association https://www.arizonahemophilia.org/
HFO	Hemophilia Foundation of Oregon http://hemophiliaoregon.org/
HFA	Hemophilia Federation of America http://www.hemophiliafed.org/
HCC	Hemophilia Council of California https://www.hemophiliaca.org/
WFH	World Federation of Hemophilia https://www.wfh.org/

HEMOPHILIA TREATMENT CENTERS HTC's

Hemophilia Treatment Centers:

Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology

University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/

University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/

UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org

Valley Children's Hospital
https://www.valleychildrens.org/

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

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

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Infusions

is published quarterly by **Hemophilia Foundation of Northern California**

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Contributor
Shelley Jajeh

HFNC IS GOING GREEN! STARTING IN 2022, ALL ISSUES EXCEPT OUR WINTER ISSUE WILL BE ELECTRONIC! WE ARE ELIMINATING OUR PRINT VERSIONS OF SPRING, SUMMER AND FALL