

HemophiliACTION

A publication of the Hemophilia Foundation of Southern California

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Winter, Southern California Style



In Tennis Love is Nothing, In Life Love is Everything



Hemophilia Foundation
of Southern California

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of Southern California

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Hemophili**ACTION**

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Happy Holidays

Dear Friends,

Merry Christmas and Happy Holidays. This is a time to celebrate with family and good friends. I enjoyed seeing many of you at the holiday party. The very best to all of you in the New Year.

Greg Mermilliod, President

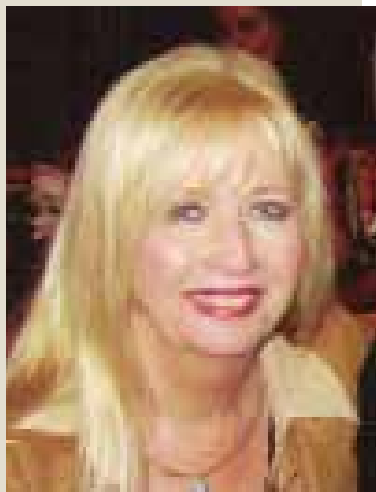


Greg Mermilliod





Executively Speaking



The Foundation celebrates the holidays and the New Year with gratitude to our community and donors for their participation and support.

Featured on our newsletter cover is a photo of children learning the great game of tennis. In tennis, love means nothing, but in life it

means everything. "Blessed is the season which engages the whole world in a conspiracy of love." -- Hamilton Wright Mabie.

Through our service this year at the Foundation, we hope that we have embodied the spirit of the holidays all year long.

"The joy of brightening other lives, bearing each others' burdens, easing other's loads and supplanting empty hearts and lives with generous gifts becomes for us the magic of Christmas." -- W. C. Jones

Our educational events have been well attended, with an outstanding summer camp with over 100 youth and 16 big stick awards. Our financial supporters have remained constant, which has allowed us to fund a family retreat for over 300 people. We are pleased that we are able to fund a social worker on a consultant basis for improvement in our family services. With increased funds, we are able to improve services and maintain a high attendance at our camp and programs.

For 2012, we have a full agenda and note that our first event will be on February 25th, so mark your calendars. I would encourage you to send me your articles and photos for future newsletters and our new website.

Together we can brighten other lives and I personally appreciate your feedback and input to improve our services. This is my wish for you: peace of mind, prosperity through the year, happiness that multiplies, health for you and yours, fun around every corner, energy to chase your dreams, joy to fill your holidays! -- D.M. Dellinger

At Christmas play and make good cheer, for Christmas comes but once a year. -- Thomas Tusser

Christmas gift suggestions: To your enemy, forgiveness.

To an opponent, tolerance. To a friend, your heart. To a customer, service. To all, charity. To every child, a good example. To yourself, respect. -- Oren Arnold

Christmas is not a time nor a season, but a state of mind. To cherish peace and goodwill, to be plenteous in mercy, is to have the real spirit of Christmas. -- Calvin Coolidge

Happy Holidays to You and Yours,
Linda Corrente

A handwritten signature of Linda Corrente in cursive.



Appreciation Lunch for Pharmaceutical donors



Wine tasting event

Hablando Ejecutivamente

La Fundación celebra los días festivos y el Año Nuevo con agradecimientos a nuestra comunidad y donaciones por su participación y apoyo.

Incluido en frente de nuestra revistas una foto de niños aprendiendo como jugar tenis. En tenis, el amor no significa nada, pero en la vida significa todo. "Bendecida es la temporada que incluye a todo el mundo es una conspiración de amor." --Hamilton Wright Mabie.

A través de nuestros servicios este año en la Fundación, esperamos que hayamos personificado el espíritu de los días festivos durante todo el año.

"El placer de alegrar las vidas de otros, aceptar las dificultades de otros, ayudar a otros y suplementar corazones vacíos y vidas con regalos generosos se convierte en la magia de Navidad." -- W. C. Jones

Nuestros eventos educativos has sido bien participado, con un campamento de más de 100 jóvenes y 16 premios Big Stick.

Nuestros apoyantes financieros han mantenido constante apoyo los cales nos han permitido patrocinar el retiro familiar de mas de 300 personas. Estamos orgullosos de patrocinar a un trabajador social como consultante para mejorar los servicios para nuestras familias.

Con fondos aumentados, podemos mejorar servicios para mantener participación alta participación a nuestro

campamento y programas.

Para el 2012, tenemos una agenda que nuestro primer evento del año es febrero 25, así que marquen sus calendarios. Los animo a que nos envíen sus artículos y fotos para revistas y para nuestro lugar de la red.

Juntos podemos alegrar las vidas de otros y personalmente aprecio sus comentarios de cómo mejorar nuestros servicios.


¡¡Este es mi deseo para Ti: paz mental, prosperidad a través del año, felicidad que se multiplique, salud para Ti y tu familia, diversión en cada esquina, energía para seguir sus sueños, felicidad ara llenar sus día festivos!-- D.M. Dellinger

"Durante la temporada de Navidad diviértase y celebra, ya que Navidad solo viene una vez al año."--Thomas Tusser

Regalos sugeridos para Navidad: Para su enemigo, perdón. Para su oponente, tolerancia. Para su amigo (a), su corazón. Para un cliente, servicio. A todos, caridad. Para un Niño, un buen ejemplo. Para Ti, respeto.. --Oren Arnold

Navidad no es una temporada, pero un estado mental. Para celebrar paz y Buenos sentimientos, para ser pleno y cálido, es de tener espíritu real de Navidad.-- Calvin Coolidge
Felices Dias festivos para Usted y su Familia,

Linda Corrente



Brothers Healthcare
BONDED BY BLOOD

- We are here 24 hours a day, 365 a year. Hemophilia doesn't take a break and neither do we.
- We provide personalized services to match your family's unique needs.
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- We coordinate nursing services that come to you, on your schedule.
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- We are community advocates, educators, volunteers, and your child's mentor.

Contact: (877) 276-4248 www.brothershealthcare.com

Spotlight: Stephen and Toni Dowling

The Foundation would like to recognize our dear friend Stephen Dowling and wife Toni for their generous support throughout the years.

Born in 1957, Stephen, who has severe Hemophilia B, moved out to Los Angeles from Iowa shortly before his 8th birthday with his family in anticipation of the newly established Hemophilia Treatment Center in Orthopaedic Hospital. Dr. Carol Kasper of Orthopaedic Hospital had been conducting research in the late 1960s and early 1970s which is how Stephen first learned that his hemophilia was due to a genetic mutation instead of a family history. He attended Eagle Rock High School until 1975 where he was encouraged by staff at Orthopaedic to participate in sports such as the swim team where he was able to develop physically and build comradeship with his classmates. Upon completion of high school, Stephen attended Glendale Community College (GCC) and later transferred to Cal State Los Angeles (CSLA) with a major in Electrical-Engineering. It was at GCC when he first heard about the Foundation's scholarship program and it is also where he first met Toni, his future wife. Toni had been an Office Administrator at the Foundation in the late 1970s and early 1980s and had been the one to answer the telephone each time Stephen called to inquire about the scholarships. Stephen continued to apply for the scholarship each semester and was approved every time until his graduation in 1982.

Stephen's first involvement with the Foundation was as a volunteer at the fundraising effort of Bingo and in 1981, as a counselor at the 2nd annual Summer Camp. He recalls that it was his first venture as a counselor and definitely a memory he will keep for the rest of his life. Summer Camp had offered activities that were carefully planned

to encourage safe participation for everyone such as pinewood derby, swimming, fishing, archery, and more, and he remembers that at the end of the week, many of the shy kids were able to come out of their shells and start sharing. For Stephen, camp allowed him to meet other people with hemophilia and gave him a greater understanding of what other bleeding problems existed for others and



how to deal with them as well as develop lasting friendships. "It provided a period where everyone would feel a 'normal' life where hemophilia was just something to be dealt with and overcome." One of his greatest joys about summer camp was that kids learned to self-infuse and helped children to be responsible for their own care. Another unforgettable memory was when in 1982, Dr. Lois Boyden of Orthopaedic Hospital started a three-day, two-night overnight camping trip for the older teenagers where Stephen witnessed two brothers making a 5-mile hike on crutches with full back-packs and everyone helping each other out to the top. It was an adventure that most campers will never forget. Currently, Stephen and his wife have been generous donors of the Foundation which enables programs such as Summer Camp to continue on with these activities.

Stephen and Toni continued to be involved with the Foundation in the 80s and in 1982, Stephen joined the Board of Directors where he was involved in activities such as summer camp, fundraisers, scholarships, support groups, Family Information Day, and more. He married Toni in December of 1989 and currently has no children but a lot of beautiful nieces and nephews.

"I became involved with the Hemophilia Foundation of Southern California when I was 22 years old. Before that all I knew about hemophilia was what I was taught about the mechanics, considerably so, of hemophilia at the Hemophilia Treatment Center at Orthopaedic Hospital. With the opportunity to join the summer camp and my experiences with the hemophilia community, it has taught me more things about living and dealing with hemophilia and what I can do and accomplish in spite of my boundaries."

– Stephen Dowling

Enfoque: Stephen y Toni Dowling

La Fundación quiere reconocer a nuestros queridos amigos Stephen Dowling y a su esposa Toni por su generosidad y apoyo a través de todos los años.

Nacido en 1957, Stephen, quien tiene Hemofilia B severa, se movió a Los Angeles de Iowa después de su 8avo año con su familia, en anticipación de la apertura del Nuevo Centro de Tratamiento en el Hospital Ortopédico. La Dra. Carol Casper del Hospital Ortopédico había estado haciendo investigaciones en los 1960's y 1970's que fue como Stephen supo que tenía hemofilia por causa de una mutación genética, y no por causa del historial familiar. El fue a Eagle Rock High School en 1975 en donde lo animaron los que lo cuidaban en el Hospital Ortopédico, a participara en deportes ya que había un equipo de natación, en el cual el podía desarrollarse físicamente y podía tener mejor relaciones con sus compañeros. Después de haber completado High School, Stephen estudió en Glendale Community College (GCC) y después se transfirió a Cal State Los Angeles (CSLA) con un enfoque en Ingeniería Eléctrica. Fue en GCC cuando el escucho sobre la beca de la Fundación de Hemofilia y fue en donde el conoció a su futura esposa Toni. Toni había sido una Administradora de la Fundación a los finales de los 70's y el comenzó de los 80's, y fue quien contesto el teléfono cada vez que Stephen llamo a preguntar sobre la beca escolar. Stephen continuo aplicando para la beca cada semestre y fue aprobado cada vez hasta

el día de su graduación en 1982.

Stephen primero se involucro con la Fundación como voluntario y recolectando fondos con Bingo en 1981, como consejero en el Segundo anual Campamento de Verano. El se acuerda que fue su primera aventura como consejero y definitivamente un recuerdo que el tendrá para siempre. El Campamento de Verano le ofreció actividades que eran planeadas cuidadosamente para animar participación segura para todos tales como el Pinewood Derby, natación, pesca, y mucho mas, y como él lo recuerda que al final de la semana, muchos de los niños tímidos podían salir de su timidez y empezaban a compartir. Para Stephen, el campamento le permitía conocer a otras personas con hemofilia y le daba un mejor conocimiento de las otras enfermedades sanguíneas que existían para otros y cómo lidiar con ellas, y también como crear amistades para siempre. "Me proveía un periodo en donde todos se podían sentir normales, y la hemofilia era algo con lo que se lidiaba y se sobrepasaba." Uno de los momentos más felices del Campamento de Verano era cuando los niños aprendían a darse su propia infusión y ayudaban a que los niños fueran responsables de su propio cuidado. Otro recuerdo inolvidable fue en 1982, cuando el Dr. Lois Boyden del Hospital Ortopédico, empezó un viaje de acampar de tres días, dos noches para los jóvenes mayores, en donde Stephen fue testigo de dos hermanos que hicieron

una caminata de 5 millas en muletas con maletines llenos y ayudándose a sí mismos hasta llegar a la cima. Fue una gran aventura que muchos de los campistas nunca olvidaran. Actualmente, Stephen y su esposa has sido donantes generosos de la Fundación lo cual permite programas tales como el campamento de Verano a que continúan con estas actividades

Stephen y Toni continúan involucrados con la Fundación en los 80's y en 1982, Stephen se unió la Junta de Directores en donde el estuvo involucrado en eventos tales como el campamento, recolección de fondos, becas, grupos de apoyo, Día de Información Familiar, y más. Se caso con Toni en diciembre de 1989 y actualmente no tienen hijos o hijas pero tiene sobrinos y sobrinas.

"Me involucre con la Fundación de Hemofilia de Sur de California cuando tenía 22 años. Antes de eso todo lo que sabía de hemofilia fue lo que me habían enseñado en mecánica, considerable, de hemofilia en el Centro de Tratamiento de hemofilia el Hospital Ortopédico. Con la gran oportunidad de unirme al campamento de verano y mis experiencias con la comunidad hemofílica, me ha enseñado mas de cómo vivir y lidiar con la hemofilia y lo que puedo realizar sin importar mis límites..."

– Stephen Dowling

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Helpful Resources for the Bleeding Disorders Community

Medic Alert Foundation - Kid Smart membership is a special service that ensures children and teenagers 17 and under, with no known conditions, or those with medical conditions, allergies or special needs are protected with our live 24/7 emergency response and family notification service. Contact: 888.633.4298 | www.medicalert.org.

Legal Aid Los Angeles -The Legal Aid Foundation of Los Angeles (LAFLA) is the frontline law firm for low-income people in Los Angeles. LAFLA is committed to promoting access to justice, strengthening communities, fighting discrimination, and effecting systemic change through representation, advocacy, and community education. Contact: 800.399.4529 | www.lafla.org.

Home Energy Assistance Program (HEAP) - The state of California offers this program to help low-income individuals with overdue gas or electric bills. HEAP also offers a rebate program. Contact: Los Angeles – 213.989.3215 / 213.989.3233. Orange County – 714.839.6199 | www.csd.ca.gov.

United Way - Brings people together to fight poverty across L.A. County and improve the quality of life for everyone in our communities. Contact: Los Angeles – 213.808.62201. www.unitedwayla.org.

The Salvation Army Southern CA Divisional Headquarters - A non profit charitable organization with numerous worship centers, social services and community programs. Contact: 562.264.3679 | www.salvationarmy-socal.org.

American Red Cross Los Angeles Region - Red Cross Los Angeles Region offers help preventing, preparing for and responding to life-threatening emergencies. Contact: Los Angeles – 310.445.9900. Pomona – 909.859.7006. Van Nuys – 818.842.5295. Ventura County – 805.987.1514 | redcrossla.org.

World Harvest Food Bank - World Harvest Food Bank is a non-profit organization that serves families in Los Angeles and surrounding cities. We assist these families by offering food, basic staples and other living essentials. Contact: 213-746-2227 | www.worldharvestfoodbank.org.

Tri City Mental Health - Established in 1960, Tri-City Mental Health Center (TCMHC) was conceptualized as a comprehensive mental health service provider, dedicated to helping families and individuals of all ages reach their full potential. Contact: 909.623.6131 | www.tricitymhs.org.

Family Services of Pomona Valley - Family Service of Pomona Valley provides counseling to help individuals and families cope their problems. Like the community we serve, our staff members represent a variety of ethnic backgrounds. Contact: 909.620.1776 | www.familyserviceofpomona.com.

Pacific Clinics - Pacific Clinics, a private, non-profit community behavioral healthcare agency, was established in 1926 as Pasadena Child Guidance Clinic. Contact: 909.625.7207 | www.pacificclinics.org.

Van Nuys Community Programs - School police, Van Nuys Police Officers, and school Principals work together to maintain a safe environment for our youth to attend school. Contact: 818.756.8375 | <http://www.lapdonline.org>.

Van Nuys Juvenile Impact Program (Boot Camp) - This program is designed to target at risk juveniles through police officers, detectives, LAUSD, Probations Dept and court referrals in an effort to instill a positive, permanent change in their behavior. Contact: 818.374.9410 | www.lapdonline.org/juvenile_division.

Community Enhancement Services - Community Enhancement Services (CES) is a non-profit

community based organization, which serves the residents of the Los Angeles County. Contact: www.cesinla.com.

Salvation Army - The Salvation Army, an international movement, is an evangelical part of the universal Christian Church. Contact: Los Angeles – 818.845.7214. San Bernardino – 909.888.1336. Ontario – 909.986.6748. Redlands – 909.792.6868. Pomona – 909.623.1579 | www.salvationarmyusa.org.

CAP Moreno Valley - The Community Assistance Program (CAP) is a private non-profit food pantry. Contact: 951.485.7792 | www.mvcap.org.

Share Program - SHARE is a Riverside Public Utilities (RPU) program that assists qualified, low-income residential customers with their utility bills and deposits. Contact: 951.782.0330 | www.riversideca.gov.

Community Action Partnership of Riverside County - The Community Action Partnership of Riverside County's purpose is to eradicate poverty by removing barriers and enabling the poor in the pursuit of economic security. Contact: 951.955.4900 | www.capriverside.org.

Community Action Partnership of San Bernardino County (CAPSBC) - CAPSBC is one of the 1,000 Community Action Agencies nationwide dedicated to assisting low-income individuals and families to become stable and self-reliant. Contact: 909.723.1500 | www.sbcounty.gov/csd.

Inland Valley Hope Partners - Inland Valley Hope Partners is a partnership of local churches, business, and non-profits that have combined services to provide people with help. Contact: 909.622.3806 | www.inlandvalleyhopepartners.org.

Family Service Agency San Bernardino - The agency's purpose is to promote and strengthen individual and family life through a variety of crisis intervention, counseling, education and community service programs. Contact: 909.886.6737 | www.familyasb.org.

Community Development and Housing (San Bernardino County) - This division runs the homeless prevention and rapid re-housing program. It is funded by stimulus dollars, and can help families avoid an eviction from their home or apartment. Contact: 909.388.0800 | www.sbcountyadvantage.com.

Hearts & Lives - Hearts & Lives collaborates with governmental and non-profit community resource providers to address the needs of residents in the Rim Mountain Communities by providing direct services and referrals. Contact: 909.589.0723 | www.heartsandlives.org.

Samaritans Helping Hand - Samaritan's Helping Hand is a non-profit corporation and a United Way Agency for Emergency Services of Food Assistance, Utility Assistance, and Other Programs. Contact: 760.243.5933 | www.vvo.com.

Desert Sanctuary Inc. - Desert Sanctuary offers services to those who have experienced domestic violence, including legal advocacy, housing and shelter, food, child care, clothing, and job finding services. Contact: 760.256.3733

Catholic Charities of San Bernardino - Catholic Charities exists to provide essential social services that increase the stability, health, and safety of low-income families and those in crisis throughout San Bernardino and Riverside Counties. Contact: San Bernardino – 909.388.1239. Orange County – 714.347.9600 | www.ccsbriv.org.

CARE/FERA (California Alternative Rates for Energy, Family Electric Rate Assistance) - CARE

provides discounts on the electric bill or gas bill. The utility company providing the discount will determine if the individual qualifies for CARE or FERA, whichever is the greater savings for the customer. Contact: 714.839.6199 | www.sce.com.

Santa Barbara Assistance Programs - Charity organizations, non profits, and other groups in Santa Barbara and Santa Maria will be receiving hundreds of thousands of dollars that will be used to provide housing assistance, prevent evictions, and help the homeless. Organization receiving funds include: Good Samaritan Shelters/Catholic Charities – 805.965.7045. The Legal Aid Foundation of Santa Barbara County – 805.963.6754. Peoples Self-Help Housing Corporation – 805.962.5152 | www.needhelpayingbills.com.

Alexander House Foundation (Santa Barbara County) - This is a program that offers financial assistance and grants for housing to fixed income seniors and long time residents. Emergency grants are available for paying for rental deposits, moving, dental bills, prescription medications, medical expenses, clothes and food. Contact: 805.966.3665

Housing Authority (Santa Barbara County) - This local non-profit agency helps with a variety of housing issues, developing and managing housing assistance programs for low-income households. Contact: 805.967.3402 | www.hasbarco.org.

Community Action Commission of Santa Barbara County (CAC) - CAC is an established non-profit social service agency providing services to approximately 10,000 low-income individuals and families. Contact: 805.964.8857 | www.cacsb.com.

Eastside Neighborhood Medial and Dental Clinic - Santa Barbara Neighborhood Clinics is the critical health safety net for Santa Barbara County and provides care to almost 17,000 unduplicated low-income patients each year. Contact: 805.963.1641 | www.sbcclinics.com.

Free medical clinics offering a variety of health and medical care - All of these clinics provide services to people who are working poor, or who lack health insurance and access to government assistance programs: Medically Indigent Adults – 805.681.5399. Franklin Public Health Clinic – 805.568.2099. Santa Barbara County Health Clinic – 805.681.5488.

Medical centers offering health and or dental care to the low income and uninsured, underinsured, on a sliding fee scale - Carpinteria Public Health Clinic – 805.560.1050. Santa Barbara County – 805.560.1050. Sansum Clinic – 805.566.5080.

Consumer Credit Counseling of Santa Barbara - Consumer Credit Counseling Santa Barbara is a non-profit, and also HUD approved foreclosure counseling agency. Contact: 800.254.4100 | www.curadebt.com.

Community Services & Development (CSD) - The CSD department manages various federal programs that help lower income families achieve and also maintain self-sufficiency, help them with paying their home energy bills, and also aids them in finding and residing in housing that is free from the dangers of lead hazards.

Community Services Block Grant (CSBG) - The Community Services Block Grant program was created to help provide a range of services to assist low-income families and people in attaining the knowledge, skills, and motivation that is necessary to achieve self-sufficiency. This program will also provides low-income people with immediate life necessities such as shelter, food, and health care needs, etc. Contact: www.csd.ca.gov.

New Practice Guidelines for HCV Genotype 1

In October, the American Association for the Study of Liver Diseases (AASLD) approved a new practice guideline for the treatment of genotype 1 chronic hepatitis C virus (HCV) infection. Approximately 70% of people with HCV have genotype 1. The lead author of the guideline was Marc Ghany, MD, from the Liver Diseases Branch of the National Institute of Diabetes and Digestive and Kidney Diseases.

The new guidelines are for use by physicians. They include the addition of one of the two new protease inhibitors (boceprevir and telaprevir), to standard HCV treatment regimens. On May 13, 2011, the FDA approved Merck's boceprevir under the brand name Victrelis™. On May 23rd, it approved Vertex Pharmaceutical's telaprevir under the brand name Incivek™. The first new HCV therapies in 10 years, both products represent a new class of drugs called direct-acting antivirals that prevent viral enzymes from replicating.

The current standard of treatment combines weekly injections of pegylated interferon and a daily ribavirin oral pill. However, that regimen is not ideal—nearly 50% of patients do not respond to it. Those who do, often experience debilitating side effects that can last the duration of the treatment—either 24

or 48 weeks.

The new drugs help boost the success of HCV treatment, protecting patients from the potentially severe and life-threatening impact of HCV symptoms, which include liver cancer, cirrhosis, end-stage liver disease and liver failure. Success is measured by patients' ability to "clear" the virus by achieving a sustained virological response (SVR) for at least six months after completing therapy. Though not technically a cure (HCV is often not completely eradicated from the liver), SVR is still the goal for clinicians. Lowering the viral load to undetectable levels in the bloodstream diminishes the disease's harmful effects.

The inclusion of a protease inhibitor increases the likelihood that a patient with HCV genotype 1 will reach SVR in up to half the time—24 weeks vs. 48 weeks. The guidelines also note that a blood-based genotype test can be used to predict responses to HCV treatment with pegylated interferon, ribavirin and either of the protease inhibitors.

"Recommendations suggest preferred approaches to the diagnostic, therapeutic and preventive aspects of care," said Ghany and coauthors. "They are intended to be flexible, in contrast to standards of care,

which are inflexible policies to be followed in every case." That flexibility will be necessary as treatment schedules will vary between patients and side effects will need to be managed carefully. The new drug regimen is not recommended for people with post-transplant HCV or those co-infected with HCV and HIV.

"Hepatologists, gastroenterologists, and others who treat patients with chronic hepatitis C now have the option of two newly approved drugs that directly interfere with the ability of the hepatitis C virus to persist in the patient," said Gary Davis, MD, chair of AASLD's special interest group on hepatitis C. "Administration of these drugs is not straight-forward and increases the complexities of patient management. The new AASLD guidelines review how and when to use these agents in the clinic. This timely document should be a great asset in the management of our patients with hepatitis C."

The new guidelines were published in the October 2011 issue of the journal *Hepatology*.

Source: Poz.com, October 7, 2011; PR Newswire press release dated September 28, 2011

Nuevas Guías de Practica para Genotipo 1 para HCV

En octubre, la Asociación Americana para el estudio del hígado (AASLD) aprobó una nueva guía de práctica para el tratamiento del genotipo 1 crónico de la infección del virus de hepatitis C (HCV). Aproximadamente 70% de las personas con HCV tienen genotipo 1. El autor líder de la guía fue el Doctor, Marc Ghany. De la Sucursal de Enfermedades del Hígado del Instituto Nacional de Enfermedades Diabéticas, Digestivas, y de los Riñones.

Las nuevas guías son para uso de los doctores. Las cuales incluyen la adición de una de dos nuevos inhibidores proteasa—boceprevir y telaprevir- al tratamiento regular de HCV en su régimen. En mayo 13, 2011, el FDA aprobó boceprevir de Merck bajo el nombre de marca Victrelis™; mayo 23 aprobó Vertex Pharmaceuticals con su medicina telaprevir bajo el nombre de marca Incivek™. La primera nueva terapia de HCV en 10 años, ambos productos representan una nueva clase de medicinas llamadas actuantes-directas antivirales que previenen que se repliquen las enzimas virales.

El estándar actual del tratamiento combina inyecciones semanales de interferón pegilado y una píldora por boca de ribavirin. Sin embargo, el régimen no es ideal—cerca a 50% de los pacientes no responden a él. Los que si responden, a menudo sufren efectos secundarios debilitantes que pueden durar el periodo del tratamiento—ya sea 24 o 48 semanas.

Las nuevas medicinas ayudan a aumentar el éxito del tratamiento de HCV, protegiendo a los pacientes de síntomas del HCV potencialmente severos, los cuales incluyen cáncer del hígado, cirrosis, enfermedad de último termino del hígado, o fracaso completo del hígado. El éxito se mide por la "habilidad" del paciente de "aclarar" el virus al llegar a un resultado sostenido virológico (SVR) por lo menos seis meses después de completar terapia. Aunque no es técnicamente una cura—el HCV es muchas veces eliminado del hígado—SVR es todavía una meta para los doctores. Disminuir la cantidad del virus a una cantidad indetectable es la sangre disminuye los efectos malignos de la enfermedad.

Al incluir el inhibidor proteasa aumenta la posibilidad de que el paciente con HCV con genotipo 1 pueda llegar a SVR en hasta la mitad del tiempo—24 semanas comparado a 48 semanas. Las guías también notan que el análisis de genotipo basado-de-sangre se puede usar para predecir la respuesta al tratamiento de HCV con interferón pegilado, ribavirin y cualquiera de los inhibidores proteasa.

"Las recomendaciones sugieren enfoque preferido a los aspectos del cuidado de diagnóstico, terapia, y prevención," dijo Ghany y coautores. "Tienen la intención de ser flexibles, en contraste al estándar de cuidado las cuales no son pólizas flexibles

para que se sigan en cada caso." La flexibilidad será necesaria ya que los horarios del tratamiento varían entre pacientes y efectos secundarios se deben manejar cuidadosamente. El nuevo régimen de medicinas no está recomendado para personas después de trasplante de HCV o en aquellos coinfectados con VIH.

"Hepatología, gastroenterología otros que tratan a pacientes con hepatitis C crónica ahora tiene la opción de dos medicinas nuevas aprobadas que directamente interfieren con la habilidad de combatir el hepatitis C en pacientes donde esta persistente" dijo Gary Davis, MD, ejecutivo de AASLD del grupo de interés sobre Hepatitis C.

"Administradores de estas medicinas no son directas y aumentan las complejidad al manejo de pacientes. Las nuevas guías de AASLD revista cómo y cuándo usar las medicinas en la clínica. Este documento debe ser un gran beneficio en manejar a nuestros pacientes con hepatitis C."

Las nuevas guías fueron publicadas en el volumen de la revista de *Hepatology* de octubre 2011

Recursos: Poz.com, octubre 7, 2011; PR Newswire press release con fecha de septiembre 28, 2011



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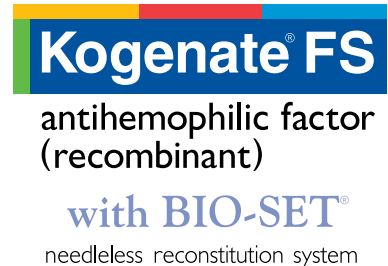
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Three Cheers for Another Fun-Packed Weekend Retreat!

It was another gorgeous sunny California weekend and we were ready to explore Malibu! This year's Weekend Retreat took place on October 21-23, at Camp Hass Kramer. We hosted over 50 families and a total of 300 people, two educational seminars, tennis classes with a professional tennis player, a yoga session and the most popular of all activities – wall climbing and ropes course.

The fun started with a kickball game for the youngsters followed by a welcome dinner. After our guests were settled in their cabins, we briefly got together for a dialogue session where members of the community discussed important issues and brought ideas and experiences to the discussion. After taking care of essential matters, it was time to dust off our dancing shoes with Chantz Powell! Chantz is part of a new generation of young artists who have discovered great music; this powerhouse entertainer had everyone dancing their socks off. We finished our first night with campfire, yummy s'mores and some sing-along with Kaylee Score.

We had a packed agenda on Saturday. The day started with a nutritious

breakfast, a workshop session and tennis classes. Workshops sessions were presented by Inalex Communications. The first session took place in the morning, with Dr. Ron Potter-Efron addressing the anxieties and stresses that parents of a child with hemophilia endure. The second session, later in the day, concentrated on discovering positive lessons in life.

The tennis classes brought happiness and a good time to all participants by giving them the opportunity to play tennis with a professional player, Scott Burton. After practicing their serves and stances our guests were ready for lunch. During the barbeque lunch, Linda Corrente, Executive Director, acknowledged the generous financial sponsors – Baxter, Bayer Healthcare, Novo Nordisk, Factor Support Network Pharmacy and Pfizer.

A special thank you was also given to the Program Committee Chair, Betsy Cook, and board members Melissa Franzen, Judy Mangione, Giovanni Pernudi and Jorge Catedral for their hard work and dedication.

The afternoon was full of activities

as well! While the ladies enjoyed some relaxing time practicing yoga, the children participated in wall climbing and ropes course, supervised by Fulcrum Adventures; and artistic workshops, face painting and arts and crafts with The Art of Elysium. We finished our Saturday with a costume themed dinner party, where participants proudly showed off their creativity in the quest for the first-place prize, and our own version special version America's Got Talent - Hemophilia Foundation's Got Talent.

Mark your 2012 calendars – HFSC Weekend Retreat, September 21-23! Accommodations are very simple, bunk beds are set-up based on space and most bathrooms are shared. The Weekend Retreat is one of our most popular events, so call to RSVP in advance, cabins are assigned on a first-come first-served basis. You will need to bring your own bed linens, towels, pillows, etc. Be prepared to enjoy nature and explore the outdoors!



Linda Corrente, Executive Director, makes announcements during mealtime



The Chen family smiles for the camera as they finish up their meal



A little girl holds up her Halloween pumpkin creation

Otro Fin de Semana Lleno de Diversión!!

¡Fue otro día caluroso y bello en California y estábamos listos para disfrutar Malibu! El Retiro de Este Fin de Semana tomo lugar el octubre 21-23, en el campamento Hass Kramer. Fuimos anfitriones de más de 50 familias y un total de 300 personas, dos seminarios educativos, clases de tenis, con jugador profesional, una sesión de Yoga y la actividad más popular- la pared para subir a las cuerdas.

La diversión empezó con un juego de pelota de los jóvenes seguido por una cena de bienvenida. Después de que nuestros invitados se arreglaban en las cabañas, nos reunimos un poco para platicar y miembros de la comunidad hablaron sobre ideas y preocupaciones importantes. Después de arreglar cosas importantes, ¡¡era hora de quitarle el polvo a nuestros zapatos de baile con Chanz Powell!! ¡¡Chantz es parte de una nueva generación de artistas jóvenes que han descubierto gran música!! Este entretenedor tenía a todos bailando. Terminamos la primera noche con una fogata, ricos dulces s'mores y cantando con Kaylee Score.

Tuvimos una agenda llena de actividades

para el sábado. El día empezó con un desayuno saludable, una sesión de un taller, y clases de tenis. Las sesiones del taller fueron presentadas por Inalex Communications. La primera sesión tomo lugar en la mañana, el Dr. Ron Potter-Efron, hablando de las ansiedades y el estrés que tienen los padres que enfrentan la hemofilia. La segunda sesión, después en el día, se concentró en descubrir las lecciones positivas de la vida.

Las clases de tenis les trajeron felicidad a todos los participante al darles una oportunidad de jugar tenis con un jugador profesional, Scottt Burton. Después de practicar varios movimientos, los participantes estaban listos para el almuerzo. Durante el almuerzo estilo barbe que, Linda Corrente, Directora ejecutiva, reconoció la generosidad financiera de nuestros patrocinadores- Baxter, Bayer Healthcare, Novo Nordisk, Factor Support Network Pharmacy y Pfizer. Un agradecimiento especial también al Comité de Programas: Líder, Betsy Cook, y miembros de la junta directiva Melissa Franzen, Judy Mangione, Giovanni Pernudi, y Jorge Catedral por

su gran trabajo y dedicación.

¡¡La tarde estuvo llena de actividades también!! Mientras las mujeres disfrutaban de un tiempo relajante en Yoga, los niños participaron en la pared de subir a las cuerdas, supervisados por Fulcrum Adventures; un taller artístico, pintura de la cara, y artes con Artde Elysium. Terminamos nuestro sábado con una cena festiva de disfraces, donde los participantes demostraron con orgullo su creatividad en su meta de adquirir el premio de primer lugar, y nuestra versión especial de America's Got Talent-La Fundación de Hemofilia Tiene Talento.

¡Marque sus calendarios del 2012- el Retiro familiar será septiembre 21-23!

Las comodidades son simples, camarotes se arreglan basados en espacio y casi todos los baños son compartidos. El Fin de semana del Retiro, es uno de nuestros eventos más populares así que llamen a reservar su espacio en avanzado, las cabañas son asignadas basado en quien llame primero. Necesita traer sus propias sábanas y cobijas, toallas, almohadas, etc. ¡Este preparado para disfrutar la naturaleza y explorarla!



Excited participants look up to see how high the ropes course extends



Children wait in line with their gear all ready to go for the ropes course



Colin Rucker waves as he gets ready for the ropes course



Don't look down! Michael Franzen holds on tight to his son Charlie



Parents meet and visit at the ropes course



The Art of Elysium performs a skit for the audience



Board members Melissa Franzen and Judy Mangione get help from Allison Franzen and Nichole Arimura sorting prizes for the talent show



Mom and daughter learn the art of face painting with the Art of Elysium



The Score family smiles for the camera as they look over the day's schedule



Children show off their costumes for the parade of costumes during the Fall Festival



The kids master tennis lessons from professional instructor Scott Burton



Juan Morris poses for the camera with Halloween pumpkins created by his kids



The girls get their faces painted during arts & crafts



Silvia Garcia and Kristian, with daughters Brooke Walsh and Alexi Garcia



It's break time during the ropes course

What Do I Do if I Suspect My Child Needs Special Education Services?

What is an IEP? An IEP is an individualized education plan that is developed so that your child's special needs will be met and adapted specifically to them. To ensure they receive an IEP that fits them correctly, trained professionals, consultants, and the special education teams will sit down to develop the IEP.

If your child has qualified for special education then the very first thing that will happen is an IEP will be developed for them. If a special education teacher mentions to you that they are developing an IEP for your child or asks you for your input, you may be confused at first. However, there is no double meaning to an IEP and your child's education. In the simplest terms, an IEP is an individualized education plan for your child that is based upon the different components of their disability. In fact, an IEP makes sure that your child receives the attention that is right for them.

Initiate Contact with your Child's Teachers - Contact your child's teachers to find out exactly where your child is having difficulty, and to determine what accommodations your child's teachers have implemented in the regular classroom environment. Oftentimes, simple accommodations such as changing a child's seat, or initialing their daily homework agenda is enough to help your child improve his or her grade.

Schedule a Student Study Team (SST) Meeting - If your child is still struggling in their classes, contact your child's counselor to schedule an SST meeting. The SST is comprised of you, your child, your child's counselor, the District Program Specialist, a representative from the Special Education Department, and your child's teachers. All members of the SST will meet in an informal meeting to review records and teacher comments and to develop suggestions and accommodations that may help your child learn better. Once the SST has met, your child's counselor will forward a copy of all suggestions

and accommodations to your child's teachers so they can implement them and determine whether or not they work.

Submit a Written Request to Have Your Child Assessed for Special Education - If after the accommodations and suggestions from the SST are implemented and your child is still struggling, you can request your child be assessed for possible Special Education Services. To do this, you must submit a written request to the District Program Specialist. The written request must state that you want your child assessed for special education services in all areas of suspected disability. It is helpful if you include in this letter the specific areas you are concerned about as well as any accommodations you have tried at both home and school to try to help your child academically. Once the District Program Specialist receives your written request, he or she will develop a proposed Evaluation Plan within 10 calendar days. This Evaluation Plan will outline the tests and assessments TPHS is proposing to administer to your child. The Evaluation Plan will be mailed to your home address for signature. As soon as you receive the proposed Evaluation Plan, please complete the Parent Acknowledgment Section. Return the Evaluation Plan to the District Program Specialist. Once the District Program Specialist receives the signed Evaluation Plan, testing will commence. The District has 60 calendar days from the date the signed Evaluation Plan is received to complete all testing and to hold an Individual Education Plan (IEP) meeting. The assessment process can be lengthy and require your child to miss approximately five hours of class time.

The IEP Meeting - During the IEP meeting, all testing results will be reviewed and the IEP team will determine whether or not your child qualifies for Special Education Services. The IEP team is comprised of an Educational Specialist, Administrative Designee, your child's counselor, a regular education teacher,

and the School Psychologist and Speech and Language Pathologist if they completed testing on your child. If your child qualifies and you chose to access Special Education Services, an IEP will be developed including academic, speech and language, and/or social emotional goals. Your child will also be assigned a case manager who is responsible for ensuring your child's IEP is followed. If your child does not qualify for Special Education, the IEP team will offer you suggestions for helping your child academically. Any suggestions offered will also be provided to your child's teachers.

Why is it important to have an IEP? It is important to have an IEP in place to ensure your child will be taught according to his or her specific needs. Oftentimes your child's progress will be assessed against the IEP that was developed for them to see how well they are doing in school since there is no one better to compare them to but themselves and their special ability levels. An IEP is flexible and will be altered and adapted throughout your child's educational lifespan since it is likely that their abilities and condition will fluctuate as well.

Annual and Triennial IEP Meetings - If your child qualifies for an IEP, this IEP will be reviewed at least annually. At the annual review, your child's IEP case manager will review the goals and rewrite or change these goals as needed. Additionally, every three years, your child will be reassessed in all areas to suspected disability to determine whether or not he or she continues to qualify for special education. If you have any questions regarding your child's IEP, you can request an IEP at any time. Once your case manager is notified you would like an IEP meeting, he or she has 30 calendar days to schedule and hold this meeting. Additionally, any member of the IEP team can also request a meeting if they have concerns about your child's educational progress.

Hemophilia Foundation Of Southern California Presented Two National Awards of Distinction

On November 12, 2012, the National Hemophilia Foundation (NHF) held its annual convention as well as the Annual Meeting Awards Ceremony in the windy city of Chicago, where the Hemophilia Foundation of Southern California was awarded two Awards of Distinction. The first award was for our new website (www.hemosocal.org), which we won in the Communications category, and the second award was for our School Nurse Outreach program, in the Health Education category. Our dear friend, Bob Miller, PA, of Children's Hospital Los Angeles was also honored for the Lifetime Achievement Award.

We strongly encourage our community members to visit our award-winning website (www.hemosocal.org) to look for updates,

news, and events. The new website is easy to maneuver and features photos, resources, calendar of events, links for applications/forms, and more! Donations are also now being accepted via the website to make for an easy and simple way to help the Foundation. If you would like to receive more information about our Foundation and its programs and services, you can send us your information via the website.

Our second award-winning program, the School Nurse Outreach Program, which began in 2009, was planned in honor of "Honor the School Nurse Day" for over 300 school nurses in the East Los Angeles school district at the Local District 5 Office in the purposes of educating and training school nurses. Guest speakers such as Ruth Ann

Kirschman, WHNP, BS, BSN, Kathleen J. Roach, MPH, MBA, and Doris Quon, MD spoke on topics ranging from von Willebrand to NHF's Victory for Women and other bleeding disorders. We look forward to the day when all the school nurses will have a basic understanding and knowledge on hemophilia and other bleeding disorders so that they will gain the skills needed to assist in the early diagnosis and management of a bleeding disorder in children and youth to prevent complications from the disease.

The Foundation would like to thank NHF as well as our community members for making it possible for us to grow as an organization with events that educate and advocate towards our cause.



Left to right: Cathy Buranahirun, PsyD – Postdoctoral Psychology/Neuropsychology Fellow, Aimée Williams, MPH, CHES, CPH – Project Coordinator Johnny Chou, MSW, LCSW – Clinical Social Worker, Silvia Vega – Social Services Case Worker, Greg Mermilliod, HFSC President, Richard Metz, MD, HFSC Past President, Linda Corrente, HFSC Executive Director, Bob Miller, PA – Physician Assistant, Connie Gallardo, NP, Kathy McGinty, RN – Nurse Coordinator

A la Fundación de Hemofilia del Sur de California se le Presenta con Premio Distintivo

En noviembre 12, 2011, La Fundación Nacional de Hemofilia (NHF) tuvo su reunión anual la cual incluyo la Ceremonia de Premios Anual en la ciudad ventosa de Chicago, donde el primer premio fue por nuestro lugar de la Red nuevo (www.hemosocal.org), el cual ganamos en la categoría de Comunicaciones, y el segundo premio fue por nuestro programa de Educación a Escuelas en la categoría de Educación de Salud.



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8:30 am - 4:00 pm
Registration at 7:30 - 8:15 am

Where: JW Marriott Hotel
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RSVP: 323-361-6465 or
HTCinfo@chla.usc.edu

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AB 389/Mitchell Becomes 2 Year Bill A Standards of Services for Clotting Factor Delivery in the Home Setting :

AB 389/Mitchell (Pavley) will now become a 2 Year Bill to be taken up sometime in 2012 before the CA State Legislature. While we were able to secure strong support from the CA State Legislature and interest groups (including the CA Pharmacists Assoc), we were not able to reach final agreement with the CA Dept. of Consumer Affairs or the CA State Board of Pharmacy on amendments to remove their opposition. We even presented a version of the recently enacted Missouri law for their consideration, which they rejected. They indicate a desire to continue talking with us during the recess. We will begin those meetings very soon.

The CA Dept. of Health Services remains neutral on the bill. They were helpful to us in getting important information to the Governor's office. We will continue to work with them, as well as the staff in the Governor's office during the Legislative Recess.

Assembly Member Mitchell and her staff were amazing. We will continue this effort into the fall months with them, DCA, and Board of Pharmacy. Hopefully we can come up with an approach to get us all where we need to be on our effort for 2012. ■

-By Terri Cowger Hill, HCC Legislative Advocate

CCS Demonstration Pilots and AB 301

AB 301/Pan will be on its way to the Governor's desk shortly. AB 301, supported by HCC, will extend the "CCS Carve Out" from most Medi-Cal Managed Care Plans in CA until January 1, 2016. We have supported similar measures in past years.

CCS Demonstration Pilots:

Meanwhile, the State of CA is moving forward with a limited number of CCS Demonstration Pilots. Those interested in submitting CCS Pilots in CA were to have submitted proposals to the State by the end of July 2011. The State is now reviewing those confidential proposals and the CCS Demonstration Pilots should be selected soon. Pilots selected are supposed to begin operating January 1, 2012, although that date could change. To learn more about those pilots go to: www.dhcs.ca.gov, on the left hand side of that web page under Quick Links click on "Current Medi-Cal Procurements", once on that page scroll down to the middle of the page and click on "CCS Demonstration Projects" for more information. We have no idea how patients with Hemophilia will be cared for under any CCS Pilot and it will be in the best interest of patients to link up with the organizers of each CCS Pilot once they are selected. We do understand that current CCS Standards must be followed in each of the pilots/ demonstration projects. ■

California Coastal Race for Hemophilia 2011

by Brian Taylor

Special Thanks to our 2011 Sponsors

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Ten years ago, U.S. Marine Corps Captain Mike Hudson decided to ride his bike down the California coast to raise funds and awareness for hemophilia. Back in 2001, Mike was joined by two other Marines and they spent eight days cycling through beach towns, farm lands, mountain passes, and city streets along California Highway 1. They started in San Francisco and ended in San Diego, and created the foundation for a one-of-a-kind event that—ten years later—is still going strong.



This year, the ten year anniversary of the California Coastal Ride for Hemophilia, nineteen riders made their way down the coast following almost the same route as Captain Hudson did in 2001. This year's riders came from all over California including a few from out of state to carry on the tradition of riding over 500 miles in seven days for hemophilia. The weather was great and the work was tough but totally worth it. Thanks to the largest crew of volunteers yet—over 17!—the riders started in San Francisco and ended in San Diego, safe and sound. Along the way, there's always a few flats and detours and sometimes your legs get sore, but there's nothing like being with friends, having fun, and supporting a great cause!

The Hemophilia Council of California exists to provide public information and to coordinate activities which will promote and ensure the welfare of all California organizations representing persons with coagulation disorders and which will directly or indirectly improve the quality of life for all persons with coagulation disorders and their families in the state of California.

Normas de los Servicios para la entrega de factor de coagulación al Hogan

AB 389/Mitchell (Pavley) se convertirá ahora en un proyecto de ley de 2 años que debe abordarse en algún momento de 2012 ante la Legislatura del estado de California. A pesar de que fuimos capaces de asegurar un fuerte apoyo de la Legislatura del Estado de California, y los grupos de interés (incluyendo la Asociación de Farmacéuticos CA), no fuimos capaces de alcanzar un acuerdo definitivo con el Departamento de California de Asuntos del Consumidor o la Consejo Estatal de Farmacia de la CA sobre la modificación de retirar su oposición. Incluso les presentamos una versión de la reciente promulgada ley de Missouri, para su consideración, el cual rechazaron. Nos comunicaron su deseo de continuar hablando con nosotros durante el receso. Vamos a comenzar las reuniones muy pronto.

El Departamento de California de Servicios de Salud se mantiene neutral en la este proyecto de ley. Fueron útiles para nosotros en comunicar importante información a la oficina del gobernador. Vamos a seguir trabajando con ellos, así como el personal de la oficina del gobernador durante el receso legislativo.

Miembro de la Asamblea Mitchell y su personal fueron increíbles. Vamos a continuar este esfuerzo en los meses de otoño con ellos, DCA, y el Consejo de Farmacia. Espero que podamos llegar a un acercamiento para estar donde tenemos que estar en nuestro esfuerzo para el año 2012. ■

-Por La Abogada Legislativa del HCC Terri Cowger Hill

Los pilotos de demostración de CCS y 301/Pan AB

AB 301/Pan:

AB 301/Pan estara en su camino hacia el escritorio del gobernador pronto. AB 301, tiene el apoyo de HCC, se extenderá la "CCS exclusión" de la mayoría de Medi-Cal planes de atención administrada en California hasta 1 de enero de 2016. Hemos apoyado medidas similares en los últimos años.

CCS pilotos de demostración:

Mientras tanto, el Estado de California se está moviendo hacia adelante con un número limitado de pilotos de demostración de CA. Los interesados en presentar los pilotos de CCS en California se han presentado propuestas al Estado a finales de julio de 2011. El Estado está revisando las propuestas confidenciales y los pilotos de demostración de CA deben ser seleccionados pronto. Los pilotos seleccionados se supone que comenzará a operar 1 de enero 2012, aunque esa fecha podría cambiar. Para obtener más información acerca de los pilotos vaya a: www.dhcs.ca.gov, en el lado izquierdo de la página web en Enlaces, haga clic en "Current Medi-Cal de Compras", una vez en esa página, desplácese hacia abajo hasta la mitad de la página y haga clic en "Proyectos de demostración de CA" para más información. No tenemos idea de cómo los pacientes con hemofilia serán atendidos bajo cualquier piloto CCS y será en el mejor interés de los pacientes para establecer vínculos con los organizadores de cada piloto CCS una vez seleccionados. Entendemos que las normas actuales CCS se debe seguir en cada uno de los pilotos / proyectos de demostración. ■

Agradecimiento especial a nuestros patrocinadores de 2011

CSL Behring

Biogen Idec

NOVO

Factor Support

Accredo

Bayer

Octapharma

Red Chip

Two Hubs

Baxter ■

Carrera Costal de Hemofilia en California por Brian Taylor

Hace diez años, EE.UU. Infantería de Marina el capitán Mike Hudson decidió montar su bicicleta por la costa de California para recaudar fondos y conciencia para la hemofilia. En 2001, Mike se unió a otros dos infantes de marina y pasó ocho días en bicicleta a través de pueblos costeros, tierras de cultivo, puertos de montaña, y las calles de la ciudad a lo largo de California Highway 1. Que se inició en San Francisco y terminó en San Diego, y creó las bases para un evento único en su tipo que - diez años después - es todavía fuerte.

Este año, el décimo aniversario de la Cabalgata Costera de California para la hemofilia, diecinueve ciclistas se dirigieron hacia la costa en casi la misma ruta que el capitán Hudson hizo en 2001. Los ciclistas de este año vinieron de todas partes de California, incluyendo algunos de fuera del estado para continuar con la tradición de montar más de 500 millas en siete días de la hemofilia. El tiempo fue estupendo y el trabajo era duro, pero valió la pena totalmente. Gracias al más grande equipo de voluntarios, - más de 17! - los ciclistas comenzaron en San Francisco y terminaron en San Diego, sanos y salvos. En el camino, siempre hay unos pocos pisos y los desvíos y, a veces las piernas se inflaman, pero no hay nada como estar con amigos, divertirse, y apoyar una buena causa! ■



El concilio para la hemofilia en California existe para proveer información publica y para coordinar actividades las cuales promoverán y aseguraran el bienestar de todas las organizaciones de California que representan a personas con enfermedades de coagulación y las cuales directamente o indirectamente mejoraran la calidad de vida para todas las personas con enfermedad de coagulación y sus familias en el estado de California.

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Hemophilia Foundation of Southern California

2012 Calendar of Events

January 25	Social Worker and Nurse Outreach & Education, Belmont Village, Hollywood
February 25	Education Forum, Skirball Center, Los Angeles
March 7-9	Washington Days- Washington DC
March 13-14	2nd National Conference on Blood Disorders in Public Health, Atlanta, Georgia
March 30-31	Hemophilia Federation of America Symposium 2012 Marriott Santa Clara, Santa Clara, CA
TBA	Family Information Day
April 29-30	Federal Hemophilia Treatment Centers/Region IX Annual HTC Conference, Santa Monica
May 7-9	Future Leaders Day, Sacramento
May 9	Legislative Day, Sacramento
June 4	HFSC Golf and Tennis Tournament, Braemar Country Club
July 30- August 4	Camp Blood Brothers and Sisters, Camp Painted Turtle
September 21-23	Family Retreat, Malibu. CA * community only
October TBD	Walk
November 8-10	NHF Annual Convention, Orlando Florida
Regional Meetings	TBA - Los Angeles, Inland Empire, Orange County, Santa Barbara/Ventura

• Dates & locations are subject to change

www.hemosocal.org Telephone: (323) 525-0440 Fax: (323) 525-0445

Hemophilia Foundation of Southern California

2012 Calendario de Eventos

Enero 25	Educación de Apoyo de Enfermeras y Trabajadores Sociales Belmont Village, Hollywood
Febrero 25	Foro de Educación, Skirball Center, Los Angeles
Marzo 7-9	Días de Washington- Washington DC
Marzo 13-14	2da Conferencia Nacional de Enfermedades Sanguíneas en Salud Pública, Atlanta, Georgia
Marzo 30-31	Simposio de la Federación de Hemofilia 2012, Marriott Santa Clara, Santa Clara, CA
SD	Día de Información Familiar
Abril 29-30	Reunión Anual Región IX de Centros Federales de Hemofilia Santa Mónica
Mayo 7-9	Día de Líderes del Futuro, Sacramento
Mayo 9	Día Legislativo, Sacramento
Junio 4	Torneo de Golf y Tenis de HFSC, Braemar Country Club
Julio 30- Agosto 4	Campamento Blood Brothers and Sisters, Campamento Painted Turtle
Septiembre 21-23	Retiro familiar, Malibu. CA * comunidad solamente
Octubre SD	Caminata
Noviembre 8-10	Convención Anual Fundación Nacional de Hemofilia, Orlando FL
Reuniones Regionales	Los Angeles, Condado de Orange, Santa Barbara/Ventura

*Fechas y lugares pueden cambiar- (SD- Sera Determinado)

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Hemophilia Foundation of Southern California

A Non-Profit Charity Dedicated to
Serving the Needs of the
Bleeding Disorders Community.



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Dan Goodwin with Novo Nordisk lends a hand at the Holiday Party