Entrevista con Katherine Register

Interview with Katherine Register

por Guillermo Sánchez / by Guillermo Sánchez

Kathy – as her friends call her – was named HNC’s 2012 Volunteer of the Year for her commitment and enthusiasm helping the chapter to achieve its goals. We are honored to show to all of you the first part of a short interview with this caring wife, loving mother, amazing woman, and friend.

G(uillermo): ¿Cómo se involucró en el movimiento de desordenes sanguíneos en Carolina del Norte?

K(athy): Mi esposo Charles, de 40 años, tiene hemofilia severa A (deficiencia de Factor VIII). Nosotros hemos sido miembros y trabajados para HNC, desde los años 70s, cuando la Asociación era todavía una filial de la National Hemophilia Foundation. A finales de los 90s, ambos éramos parte en la mesa directiva de la Asociación y contribuimos a que ésta se constituiera como una entidad independiente. Después de un periodo de alejada de la Asociación, regresé con mucho gusto para ocupar el puesto de tesorera dentro de la mesa directiva, función que desempeño desde el 2007. El año pasado, al salir Sue Cowell, fui nombrada directora ejecutiva interina por un periodo de tres meses. Mi esposo Charles desarrolló nuestra pagina en internet - la cual se ha ganado el premio a mejor portar de internet-, y continua a su cargo.

G: Parece ser que estamos ante una honorable miembro de HNC y que todo el trabajo que le has dedicado a la Asociación es invaluable. En verdad aprecio cuando la pareja de una persona con algún desorden sanguíneo, se involucre de tal forma en ayudar a nuestra comunidad, que comienza a ser una pieza esencial dentro del equipo de trabajo y contribuye a traer beneficios para sus miembros.

K: Mi compromiso en beneficio de la comunidad de desordenes sanguíneos es de por vida. Al separarme oficialmente del puesto de tesorero de la Asociación, continuare realizando esta función hasta que algún otro voluntario se haga cargo, o hasta que la mesa directiva me pida que deje de realizar este trabajo. Estoy segura que puedo hablar en lugar de Charles al decir que nosotros dos preferimos el trabajo “detrás del escenario” en vez de estar en el centro de atención, y no puedo imaginarme a ninguno de los dos dejando de apoyar a la comunidad.

G: Me alegra escuchar que tendremos el apoyo de Los Registers indefinidamente. El Programa de la Unión Latina ya ha sido benefi-

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Kathy, como la llaman sus amigos, fue nombrada Voluntaria del Año, reconociendo su compromiso y entusiasmo que entrega al realizar las actividades dentro de la Asociación. En esta edición tenemos el honor de presentarles la primera parte de una corta entrevista con esta extraordinaria esposa, madre y amiga.

G(uillermo): ¿Cuántanos acerca del como comenzaste a involucrarte dentro de la comunidad de desordenes sanguíneos en Carolina del Norte?

K(athy): Mi esposo Charles, de 40 años, tiene hemofilia severa A (deficiencia de Factor VIII). Nosotros hemos sido miembros y trabajados para HNC, desde los años 70s, cuando la Asociación era todavía una filial de la National Hemophilia Funding. A finales de los 90s, ambos éramos parte en la mesa directiva de la Asociación y contribuimos a que ésta se constituiera como una identidad independiente. Después de un par de años alejada de la Asociación, regresó con mucho gusto para ocupar el puesto de tesorera dentro de la mesa directiva, función que desempeño desde el 2007. El año pasado, al salir Sue Cowell, fui nombrada directora ejecutiva interina por un periodo de tres meses. Mi esposo Charles desarrolló nuestra pagina en internet - la cual se ha ganado el premio a mejor portar de internet-, y continua a su cargo.

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Me gustaría que ahora me platicaras sobre tus planes para el futuro. I am guessing and hoping that you are planning to stick around supporting our community for more years, right?

K: I am committed to the bleeding disorder community for life. While I have stepped off the board as of July 1 this year, I will continue to work at home as de facto Treasurer of the organization until someone else volunteers for the position, or until I am asked to step down. I think I can speak for Charles when I say that both of us prefer working “behind the scenes” rather than “in the limelight” and I do not foresee either of us ever stopping this work.

G: I am glad to hear we will have the Registers around indefinitely. The Latin Union program has already been invaluable! I really appreciate when the partner of a person with bleeding disorder gets involved in our community to the point of being an essential piece within the task force that makes things happen for our benefit. I bet you and Charles inspire each other to continue with all this invaluable work. (By the way congrats Charles for stepping in and taking care of the HNC business as an interim Executive Director!!! You guys rock!)

Now, I would like to hear about your plans for the future. I am guessing and hoping that you are planning to stick around supporting our community for more years, right?

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benefited from your experience and commitment. I am sure most people will agree when I say that being “behind the scenes” is the hardest but most rewarding work when working on a team.

I guess the second question is about your exposure/contact with the Latino community either in a professional or personal level?

K: Because Charles and I are retired, we have no professional exposure of any kind at this time. On a personal level, the Latino community is a part of my family, because my first cousin is Argentinian, lives in Buenos Aires, and is Spanish-speaking. But I am a bit embarrassed to say that I speak very little Spanish. My cousin speaks English quite well, so I have not (yet!) had a compelling reason to learn Spanish, although I have been wanting to for quite some time.

G: What is your opinion on the HNC decision to create a program to serve the Spanish-speaking community living with bleeding disorders in NC?

K: I was very excited when HNC initiated the Latin Union program, which has enjoyed generous support from Baxter. I am very proud of it and hope to see it grow. There should be no political, cultural, or language barrier when it comes to getting good health care. I know how scary and distressing it is to have hemophilia in the family. It must be doubly scary living in a culture that is not your traditional one, and which uses a language not your own.

G: You have just used two of the words that better describe the feeling that is affecting most of the Latino families living in NC: scary and distressing. I am always looking for people who know what a family member of someone with bleeding disorder would do in order to obtain not just good health care but the right treatment to keep their beloved one alive and out of pain. So I would like you to imagine that you are standing in a podium in front of Latino families living with someone affected by a bleeding disorder. What would you say to them to cheer them up? And what advice would you have for them (how to “survive” in this country, strategies to cope, etc.)?

Calendario de Reuniones / Meeting Calendar · Sábado, Junio 22, Bienvenido Verano, Concord, NC · Septiembre 14 y 15, 3rd Retiro Familiar del Grupo de La Unión Latina. Para mas información llama a Guillermo Sánchez: 855-462-5286 o escribenos un email union.latina@hemophilia-nc.org
K: First of all, I would need a translator! I would say two things:

1. Our biggest challenge is no longer the science and technology of treating bleeding disorders, it is access to care. It is unfortunate that access to care has become such a heated political issue. There is a lot of ignorance and misunderstanding, which have become a foundation for fear and discrimination. Of course we see some political eras which are worse than others—but we are in the middle of a tough time right now.

Yet, the Affordable Care Act (ACA) offers promise and hope in the years to come. Despite what we are seeing now in North Carolina --- a sometimes horrifying bureaucracy and political push-back, as well as discrimination---the majority of Americans are compassionate people. As history is our guide, the pendulum will swing and the succor that is a part of our nature will continue to become institutionalized at the local and national levels. Meanwhile, we as a community must band together and help each other through this phase.

2. The progress I have seen in treatment of bleeding disorders since I met Charles in 1970 has been miraculous—even for people with inhibitors, musculo-esquelético, enfermedades de la sangre, and especially...
paras las mujeres con algún tipo de desorden sanguíneo. Y aún, están por venir nuevas opciones de tratamiento que cambiarán definitivamente—y para su beneficio—a nuestra comunidad. Cambios que van desde la eficacia en la disminución de sangrados a la cura de enfermedades infecciosas, y de inventos que ayudarán a mejorar la movilidad y la salud en general. Hoy en día a un bebé nacido con algún desorden sanguíneo le espera un futuro brillante. Yo aún sueño con el día en que puedan ser curados los desordenes sanguíneos, que se puedan crear nuevos, y saludables extremidades utilizando células madre. Espero vivir (tengo 61 años) para verlo. Muchos de ustedes de seguro lo harán.

G: La Comunidad Latina de Desordenes Sanguíneos puede atestiguar acerca de la compasión y hermandad entre las familias que enfrentan esta condición de salud sin importar nacionalidad. Nuestras familias latinas en verdad se sienten parte de la comunidad de HNC. Es mucho más sencillo adaptarse a otra cultura cuando tienes a alguien que te guíe y te apoye en tan distintos sistemas político y de salud.

No te pierdas la parte final de esta entrevista en nuestro siguiente numero de The Concentrate – Otoño 2013– y entérate de las sugerencias que Kathy ofrece a todas las parejas de personas que padecen algún desorden sanguíneo!

Baxter’s vision is a life without bleeds

At Baxter, we will not stop until our vision of a life without bleeds is a reality for all.

Over the years, Baxter has been the leader in providing support and resources for the community.

Today, we are continuing to improve treatment for bleeding disorders. We have seven ongoing clinical trials, including those targeting hemophilia A, hemophilia B, inhibitors, and von Willebrand Disease.

For people with bleeding disorders, the future has never been brighter. As we increase the time between infusions, someday regular infusions, as we know them, may be distant memories.

To us, continuing to make a meaningful difference one person at a time is our passion and what’s behind our unwavering commitment.

Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.