Dream Job of a Lifetime

-Joyce Strazzabosco

My 45-year career was spent in nonprofit organizations, with the last 38 being in management positions. Nonprofits never have enough money to fully address their missions. That means I spent substantial time managing fundraisers and writing grants to Federal, State, County and City Governments, United Way, and private foundations. I used to dream of being on the other side of table, of being in a position to give away money. Enter Joe Pugliese, the President of The Hemophilia Alliance, a national membership organization of federally funded Hemophilia Treatment Centers.

I ran into Joe at the 2008 Annual Meeting of the Mary M. Gooley Hemophilia Center, my local chapter and former workplace. Joe asked for my phone number, saying he had something he wanted to talk with me about. And a few weeks later he called. Joe talked about The Hemophilia Alliance’s plan to share its discretionary funds with organizations serving the bleeding disorders community. A grants committee was being formed, and he asked if I’d like to serve on it. I mulled it over for 2 or 3 seconds and said YES! My Dream Job had finally found me! And I was fine with the fact that there was no monetary compensation. Joe also let me know that the grants committee would be starting at zero with respect to processes, policies, forms, and any other operating material. We didn’t have to raise the money, but we did have to figure out eligibility criteria, guidelines, and what we would and would not support. A group of seven people from diverse disciplines, geographic areas, and skill sets was convened and the first grants were awarded in 2009.

In 2013, the operation was incorporated as The Hemophilia Alliance Foundation. The Foundation has a volunteer board of directors numbering 7 individuals representing, like the grants committee, individuals from diverse disciplines, geographic areas, and perspectives of the bleeding disorder community. They are: Susan Karp, RNMS, San Francisco, CA; Michelle Rice, NHF Sr. VP – Public Policy/Stakeholder Relations, Indianapolis, IN; Brenda Riske, MS, MBA, MPA, Denver, CO; Crystal Sallans, LCSW, Houston, TX; Anjali Sharathkumar, MBBS, MD, MS, Iowa City, IA; Chad Stevens, Newdale, ID; and I, Joyce Strazzabosco, Chair, Palmyra, NY. The Foundation also benefits from the donated services of the Alliance’s President, Joe Pugliese, and Vice-President, Sean Singh. Audra Ames and Joel Bellucci provide administrative and Web services, respectively.

The Foundation receives its funds primarily – and from 2009 through 2013, exclusively -- from The Hemophilia Alliance. It now also receives a generous contribution from the Hemophilia Alliance Pharmacy, and in 2016, for the first time, some independent donors have expressed interest in contributing to the Foundation.

In 2016, the Foundation made grants to 79 organizations totaling $699,000. The organizations ranged from local chapters and centers to regional and national organizations, with 81% of the funds being awarded to the local organizations and the remaining 19% going to regional and national organizations.

As with any young organization, the Foundation continues to learn and grow. Last year we refined the timeline of our application process, and published our first Grant Guidance. This single document contains everything a grant applicant needs to know to apply for funding. As anticipated, several areas for improvement came to light as applications and questions were sent in, and improvements will be made. We strive to make the process as simple as we can while assuring we get the information necessary to meet our obligations as trustees, and to assure fair and unbiased decisions.

Prior to the start of the 2017 application process, the Foundation will hold several orientation and information sessions to help applicants avoid common pitfalls that can adversely affect an applicant’s results.
More information will be posted on the Foundation’s website at www.hemophiliaalliancefoundation.org no later than October 1, 2016. In addition, email notices will also be sent, and press releases to major hemophilia communication vehicles.

People hearing about the Foundation for the first time are encouraged to go to our website, cited above, and download the 2016 grant guidance. It contains a lot of information as well as contact information should the reader have further questions.

So have I found my Dream Job to be satisfying? I’d say yes and more. It is inspiring to read the passion and dedication with which people are addressing the community’s needs. It is encouraging to see the creativity and originality in so many of the projects. It is hopeful to see more consumers being identified. And it is rewarding to know we played a small part – important, but small – part in the success of the good works that are being done in service to people with bleeding disorders. I’m really glad Joe called.

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Joyce Strazzabosco has chaired the Hemophilia Alliance Foundation since its early days as a grants committee. She was the President and CEO of the Mary M. Gooley Hemophilia Center in Rochester, NY, from 1986-1999. In that capacity she served on the NYS Hemophilia Advisory Panel, on several US HHS Maternal and Child Health committees and task forces, and in several NHF volunteer roles. She co-presented a workshop at the 2002 WFH meeting and in 2003 co-authored a WFH booklet on the same subject: Group Dynamics and Team Building, available on the WFH website.