William’s Story: A Client’s Last Wish

p. 4-5
**OUR MISSION**

The mission of AIDS Services Foundation is to prevent the spread of HIV and improve the lives of men, women and children affected by HIV/AIDS in Orange County.

**OUR STORY**

A small group of volunteers founded AIDS Services Foundation Orange County (ASF) in the late summer of 1985 because people were dying, had nowhere to turn and desperately needed help. ASF is now the largest and most comprehensive nonprofit HIV/AIDS service provider in Orange County, with a staff of committed and caring individuals, a 23-member Board of Directors, and hundreds of dedicated volunteers.

Each year, ASF helps more than 1,600 men, women and children, along with their families, that are either living with HIV or are impacted by HIV disease. Services include food, transportation, housing, case management, emergency financial assistance, children and family programs, Latino outreach programs, mental health counseling, support groups, HIV testing, and an extensive array of HIV prevention and education programs. We hope for a time when these services are no longer needed. Until then, we work hard each day to prevent the spread of HIV and to ensure that everyone living with HIV and AIDS in Orange County has access to life-enhancing care and services.
Dear Friends,

Please allow me to once again wish you all a Happy New Year as you open your first copy of the Voice for 2014. All of us at ASF wish you, our dedicated supporters, all the success, prosperity, and joy this New Year offers.

The New Year brings changes to all of us at ASF, too. One of the biggest changes will be a venue and format change for the 2014 AIDS Walk Orange County. While our three years at the Disneyland Resort were a dream come true for the agency and our walkers, it’s time to return the walk to the kind of grass roots community festival it once was. I hope, once you read all about it on page 8, that you are as excited about this year’s walk as all of us are. It’s sure to be our biggest walk in years!

Also formally debuting this year is a brand new fundraising guild… Getting to Zero. This new guild was formed out of the Getting to Zero Fashion Show that was produced last year. The core of the committee that presented that show wanted to keep working on fundraisers to benefit the agency. And that desire has grown into the guild. They’ve adopted the slogan, Getting to Zero, of World AIDS Day to inspire and define them. There’s a lot in store from this group and you can read more about it on page 9.

William Conway, an ASF client who recently passed, asked us to help tell his story. Our cover story in this issue is the fulfillment of that wish. William was very candid and forthcoming during weeks of interviews for this story. I hope you find inspiration in the forgiveness he offered his estranged family and solace in the peace he found in his last days. He attributed all of it to the help provided by his ASF case manager and nursing case manager.

As always, I am thankful for your support and look forward to seeing some or all of you at AIDS Walk this year!

Sincerely,

Philip Yaeger
Executive Director/CEO
And then, in August, we informed you that William had taken a turn for the worse, his cancer reemerging with a vengeance, and he was not expected to survive. At that time, he was meeting with Dr. Judy Runels, an ASF mental health counselor, and Darya, a volunteer, who were helping him get his story down on paper. What was to be a celebratory tale of his life has taken a sudden and sad turn.

Dr. Judy and Darya met with William for seven sessions over 8 weeks at a skilled nursing facility. What follows is his story. Knowing he was in his last few hours, it’s what he wanted us to know about him and his life. His hope was that we could all benefit from the knowledge of his experiences.

William was born in 1965. By the young age of six, he recognized that he was gay. And by the age of thirteen, he had come to accept it, although his mother hadn’t. He remembers her telling him that he could not live under her roof if he had “one gay bone in his body.”

By the age of 14, his mother kicked him out of the house. He was never allowed to say goodbye to his siblings, a sister and a brother, which left an open wound, for all parties, for years to come. He eventually landed in the foster care system.

It was a very unhappy time for William. To him, there was “nothing worse than a parent giving up on a child.” He so disliked the foster care system that he attempted emancipation. Emancipation is not easily granted to minors since there is a very narrow definition of what is exactly in their “best interest.” Ultimately, his petition failed. His only recourse was to attempt to get his lover, who was past the age of majority, to adopt him. That also failed.

At the age of 21, William contracted HIV. A year later, in 1987, he moved to San Francisco, CA, in search of a cure. He lived there for 10 years. In 1992, he was diagnosed with AIDS and went into hospice care. He was told that he would not make it out alive. He did not accept that prognosis and fought a hard battle back to health. In 1997, William left San Francisco and eventually ended up in Orange County.

During his time in Orange County, his AIDS flared and he again landed in hospice. For the second time, he was told that he would never be leaving under his own power. And for the second time, he defied the prognosis, recovered his health and strength, and resumed as normal a life as anyone with HIV can have.

William spoke of his lack of understanding of the cancer that had invaded his body. He was much more accepting of a death due to complications from HIV/AIDS. To him, there was reasoning behind that kind of death. With AIDS, there was a cause to fight for, but with cancer, he had no spirit to fight.

He could “feel the cancer grow” but didn’t know how to fight back. There was a strange irony to him that he “waited for eleven years to die of AIDS, but never did. Then meds came out for AIDS.” He knew he wouldn’t die while he was in hospice, but now he sensed he was dying.

Now that William was confronting his own death, he was overwhelmed and wanted closure.
After 37 years, William’s mother finally reached out to him to build a relationship, having heard he was dying, through Facebook. Conflicting feelings began to well inside him. He often felt it would be impossibly difficult to have his mother back in his life. His mother, absolving herself of all responsibility for the difficulty between them, placed all the blame on his shoulders. Yet, he knew he needed her desperately.

He needed to see his mother, brother, and sister before he died. And he wanted them to have the opportunity to see him again before it was too late. His mother was in denial about his impending death and that denial was driving him crazy. His siblings were angry about the situation, too. So, William took the first steps.

He had been extending his actual prognosis when he described his situation to his mother. He had been telling her that he had a year to live. “I was protecting her,” he said, “just as I’ve always done.” He finally told her the truth and she finally understood the gravity of the situation.

He also let his mother know that despite all of the blame she placed on him, he forgave her. He had forgiven her years ago. That forgiveness paved the way to a possible reconciliation and final visit. But there were still issues.

The biggest issue facing William’s mother and siblings was a financial one. She lived in Alabama and his siblings were outside of California, as well. None of them had the funds necessary for either a flight to California or a hotel stay. William would have to continue his fight. He still couldn’t see a light at the end of this tunnel.

As much and as often as he wanted to give up, and with the support of staff at ASF, he vowed to continue taking his HIV medications and “fight a little longer.” A solution would present itself. And that solution came in the form of the Dream Foundation.

The Dream Foundation grants requests from adults with life-limiting illnesses. With assistance from ASF’s volunteer Darya, William wrote a letter to the foundation and requested travel to California, accommodations, and a rental car for his mother and siblings. His desire to end his life’s journey with resolution, completion, and peace fit squarely with the foundation’s mission and his dream was granted.

William’s family visited for 5 days in July. He was overwhelmed with gratitude at the chance to gain closure. He was finally able to say goodbye to his siblings. He now felt his passing would be eased since amends were made. But he was still worried about facing his own death and felt that once his family left, he would know it was over and he would give up.

His last worry was for the well-being of his beloved dog Valentina. He didn’t want her to see him die. It was breaking his heart that she could sense it was time for him to go. But it would also break his heart if she didn’t land in a loving home.

Before his mother went back to Alabama, the decision was made. She would take Valentina back home with her. It was the right thing to do…for both of them.

In his last weeks, William struggled with all the things he had hoped to accomplish but never did. He knew it was too late for a bucket list. As much as he urged everyone else not to deny he was dying, he denied it for too long and then didn’t know how to set priorities with the short time he had left.

He wanted to take a trip to the valley. He longed to see the mountains again. He wanted to spend just one more day at Disneyland. In the end, he didn’t have the strength for any of that.

William, who once aspired to be a music therapist to help others, lost his final battle with cancer on September 3, 2013. ■
A LEAGUE OF OUR OWN
Occasionally since 1996, and on an annual basis since 2004, ASF has received support from a local bowling league, **Friday Night Trios**. 2013 was no different. At the beginning of December, the agency received checks totaling $1,850.00. This brings the league’s total support for ASF to over $12,700!

According to **Steven H. Morris**, vice president of the league, the funds donated each year are the result of an annual tournament collectively organized by Friday Night Trios members and benefiting AIDS Services Foundation. “Keep up the valuable work you do,” said Morris, “and we will continue to support your organization.”

“ASF is very grateful for the grassroots support of organizations like Friday Night Trios,” said **Philip Yaeger**, ASF executive director/CEO. “Friday Night Trios doesn’t only support ASF financially. Through their fundraising tournament, their members also provide another avenue of outreach and awareness for the agency and the cause of HIV/AIDS in Orange County.”

Formally established in 2003, Friday Night Trios is an LGBT league offering “an alternative way to meet people while participating in a healthy clean sport anyone can enjoy.” While the Spring session has already begun, interested bowlers can join the league for the Summer session beginning Friday, May 3. The next ASF Fundraising Tournament is scheduled for Sunday, October 27.

More information about the league can be found at FridayNightTrios.com or their Facebook page at facebook.com/Friday.Night.Trios.

WE’VE GOT YOU COVERED!
On March 23, 2010, **President Obama** signed the Affordable Care Act (ACA) and set into place an effort that will help ensure Americans have secure, affordable health insurance. The ACA is the most significant health care legislation since Medicare was passed in the 1960’s.

There are some exemptions, but the ACA requires most Americans currently without health insurance will be required to have some type of health insurance meeting basic minimum standards by 2014. Open enrollment, the period when you may sign up for health coverage, began October 1, 2013, and continues through March 31, 2014.

Health insurance will continue to be available through your employer, privately, or through Medicare, just as it is now. If you are currently uninsured or cannot get access through work, you can purchase private insurance through the state’s health insurance exchange, Covered California (**CoveredCA.com**). Remember, the new law requires that insurance companies provide insurance regardless of previous conditions.

To help facilitate the process of acquiring insurance for our clients and the general public, ASF has become a Covered CA Certified Enrollment Entity. We have become experts in helping others navigate the enrollment process. Several of our staff members have trained to become Covered CA certified enrollment counselors and are available by appointment to help clients, friends, family, neighbors…any Californian, really… through the enrollment process and California’s health care exchange.

We all know someone without healthcare, so the importance of everyone enrolling into a plan or talking to a loved one about Covered California is now more vital than ever. If you, or someone you know, regardless of HIV status, needs help navigating the Covered CA website and enrolling for health insurance, please contact ASF at 949-809-5700 and make an appointment with one of our certified enrollment counselors.
NEW DISCOVERY MAY EXPLAIN HOW HIV REMAINS IN THE BODY DESPITE TREATMENT

"Most human cells are short lived, so it has been unclear how HIV manages to stick around for decades in spite of very effective antiviral treatment," says Mathias Lichterfeld, MD, of the Massachusetts General Hospital (MGH) Infectious Disease Division, corresponding author of a report receiving advance online publication in Nature Medicine. "This question led to the hypothesis that HIV might infect stem cells — the most long-lasting cells in the body." A new group of T cells that have been newly discovered, called T memory stem cells, are susceptible to HIV and likely represent the longest lasting cellular niche for the virus.

Testing blood samples that had been taken from patients soon after initial infection and several years later revealed that the viral sequences found in T memory stem cells after 6 to 10 years of treatment were similar to those found in circulating T cells soon after infection, indicating that HIV had persisted relatively unchanged in T memory stem cells. In addition, the amount of HIV DNA in these cells remained relatively stable over time, even after long-term treatment caused viral levels to drop in other T cell subsets.

The researchers feel that identifying the reservoirs for HIV persistence is a critical step toward developing interventions that could induce a long-term remission without the need for antiviral medication. It could also lead to elimination of the virus entirely. "Although a real cure for HIV has been elusive," Lichterfeld said, "it is not impossible."

HIV PREVENTION PILL TRUVADA NOT FOUND TO INCREASE SEXUAL RISK BEHAVIORS

In 2012 the HIV antiretroviral drug Truvada became the first and only medication approved by the FDA for HIV prevention. Led by Gladstone Institutes' Investigator Robert Grant, MD, MPH, who is also a professor at the University of California, San Francisco (UCSF), this research was hailed as an important step towards reducing the worldwide HIV/AIDS epidemic. Now, a new study provides further proof that regular Truvada use can reduce one's risk for contracting HIV - without increasing sexual risk behavior.

Questions about the drug’s real-world effectiveness remained despite initial studies and corroborating follow-up studies, however, particularly concerning the issue of whether taking the drug could lead to a behavioral effect called risk compensation. Risk compensation is the notion that individuals adjust their behavior in response to a change in their perceived level of risk — such as increasing exposure to the sun in response to sunscreen use. While participants did self-report decreases in sexual risk behavior over the course of the study, Dr. Grant and his team decided to examine those findings more closely, by studying biological markers of risk behavior.

The multi-year study enrolled nearly 2,500 men and transgender women, at-risk for HIV infection, in Peru, Ecuador, South Africa, Brazil, Thailand, and the United States. Half of the participants were given Truvada, while the other half were given a placebo. Unaware as to whether they were being given Truvada or the placebo, participants were also asked whether they believed they were receiving Truvada — and whether they thought it was working.

"If risk compensation were occurring, those who believed they were receiving Truvada and that it was effective would be more likely to increase their sexual risk behavior," explained Julia Marcus, PhD, MPH, the paper’s first author. "However, our results revealed the opposite: rates of HIV infections went down, and there was no increase in sexual risk behavior."

The results suggest that HIV prevention strategies such as Truvada don’t result in risk compensation because they provide an opportunity for participants to actively engage in and reduce their risk of HIV infection. These findings should help to minimize reluctance to embrace Truvada over fears that it could actually lead to increased risk and more infections.

"This study reinforces the importance of drugs like Truvada as one component of a comprehensive plan for supporting people living with HIV and — importantly — preventing others from becoming infected," said Jeffrey Crowley, distinguished scholar at the O'Neill Institute for National and Global Health Law at Georgetown University and former director of the White House Office of National AIDS Policy.
The 28th annual AIDS Walk Orange County is set for Saturday, May 17, 2014! Walkers who joined us over the last few years will notice a lot of changes. And walkers who have been with us for longer will hopefully enjoy the return to the grassroots, community feeling the walk had from the beginning.

For 2014, the walk returns to the Orange County Great Park in Irvine. But the park doesn’t feel anything like it did the last time we walked there 4 years ago. So much has changed. If you haven’t visited recently, you will be pleasantly surprised! Suffice it to say, we won’t go anywhere near most of the runways that comprised that original route.

Another change this year is the opportunity to engage a whole new audience… Runners! The Red Ribbon 5k Fun Run is a new and energy-infusing event that will kick-off a few hours prior to the walk. The route will take runners along the same beautifully planted and manicured greenways that walkers will encounter once they begin.

We are also able to return to the community festival feel that walkers so enjoyed for the first few decades of the walk. We plan to have lots of family activities, food and beverage, and music to keep you entertained as you pass the early afternoon with us and thousands of your friends!

Plans are also underway to create the largest AIDS awareness ribbon the county has ever seen. The Human Red Ribbon Project is engaging hundreds of middle and high school students to walk in the event and then congregate to form a giant human red ribbon. A photograph will then be taken from the air to record our success! It’s just another way ASF and AIDS Walk are trying to get young people engaged in the HIV awareness dialogue.

Registration for the walk, run, and Human Red Ribbon Project is already open. You can register or donate today at aidswalkorangecounty.org. You can also visit that website for the most up-to-date information on all of the activities we are planning.

The registration fee is $25 per person. That amount can be paid by the participant at the time of registration or they can fundraise to cover the fee.

Walk or run as an individual, join a team, or start a team with friends, a school, a business, your faith community, or family and neighbors… but please join us!
On Thursday, August 22, 2013, at a fashion show hosted by Marc Pridmore Designs and Bettininis Fashions, supported by many more Orange County businesses, and benefiting AIDS Services Foundation, an idea was born. That idea has blossomed into ASF’s new fundraising guild, Getting to Zero.

The core of the committee that produced that amazing evening of fashion, including a stellar silent auction, decided that they wanted to continue to support ASF in the same way for the long term! Members of the committee include Zai Holder of Marc Pridmore Designs and Guy Babusek and Steven Bond, founding members of the now dissolved Friends of Dorothy Guild.

The group adopted Getting to Zero as their moniker because it is the theme of World AIDS Day through 2015. They whole-heartedly agree with, and are putting their vast talents, resources, and energy into, the initiative’s goals of…

- **Zero New Infections:**
  Sexual transmission of HIV reduced by half, including among young people, men who have sex with men and transmission in the context of sex work; Vertical transmission of HIV eliminated and AIDS-related maternal mortality reduced by half; All new HIV infections prevented among people who use drugs.

- **Zero AIDS Related Deaths:**
  Universal access to antiretroviral therapy for people living with HIV who are eligible for treatment; TB deaths among people living with HIV reduced by half; People living with HIV and households affected by HIV are addressed in all national social protection strategies and have access to essential care and support.

- **Zero Discrimination:**
  Countries with punitive laws and practices around HIV transmission, sex work, drug use or homosexuality that block effective responses reduced by half; HIV-related restrictions on entry, stay and residence eliminated in half of the countries that have such restrictions; HIV-specific needs of women and girls are addressed in at least half of all national HIV responses; Zero tolerance for gender-based violence.

Another fashion show is planned for later in the year, but to introduce us all to the new guild, Getting to Zero is planning a screening of the documentary Blood Brother.

The film is an intimate portrait of Rocky Braat, a young man who longed to find a family. He didn’t know it, but this desire would lead him to an AIDS hostel in India, a place of unspeakable hardship, where he would find almost more love and need than he could bear.

While planning is still underway for the event, once a suitable location is found for the screening, notice will go out via email to all donors alerting them of the date, location, and time.

Memberships to the guild will be sold at that time. But, even if you don’t plan on becoming a member, we hope you will join us to help make the launch of the new guild as successful as possible and to see this extraordinary documentary of love and compassion for young people living with HIV/AIDS.
Thank you very much to all of our donors for your support in 2013. The generosity of new and longtime donors alike contributed to the successes ASF achieved this year.

Special thanks are offered to those donors, appearing below, who responded to the appeal in our holiday issue of The Voice. Donations received through this annual letter campaign provide much-needed funds for general operations of the agency. Your thoughtfulness and generosity toward ASF at a time of year when many nonprofits are in need of help is humbling and very much appreciated.

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Thank you to Pacific Life and Bob Haskell on his retirement for all you have done for ASF. You were our first corporate donor in 1985.

— All your friends at ASF
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HIV/AIDS... it's no walk in the park.
But walking in the park can help!
Join us at the OC Great Park for the 2014 AIDS Walk Orange County & Red Ribbon 5K Fun Run.

AIDS SERVICES FOUNDATION ORANGE COUNTY
5.17.14

Orange County Ride for AIDS
William R. Mason Regional Park, Irvine, CA

10.25.14