



THE **REUNION** PROJECT

CREATING A **FRAMEWORK** **FOR HIV SURVIVAL**

THE REUNION PROJECT NATIONAL ROUNDTABLE FORUM
MARCH 30-31, 2018

ANNENBERG CENTER FOR HEALTH SCIENCES
RANCHO MIRAGE, CALIFORNIA

BY JEFF BERRY AND MATT SHARP

"THE REUNION PROJECT honors the history and the future of all who have survived and are living the epidemic."

CONTENTS

- 3** Background and Objectives
- 4** The Roundtable
- 5** Who We Are
- 6** The Four Themes, or 'Buckets'
- 7** Key Terms Used in Discussion
- 8** Day Two and Meeting Outcomes
- 9** Evaluation Results and Conclusions
- 10** About This Report's Authors



BACKGROUND AND MEETING OBJECTIVES

Initiated in 2015, THE REUNION PROJECT *honors the history and future of* survivors of HIV. With the advent of effective combination antiretroviral therapy, more people living with HIV are surviving and thriving than ever before. In fact the majority of people living with HIV in the U.S. today are over 50 years old, and in two years it is estimated that 70% will be over 50.

As THE REUNION PROJECT unfolded, we encountered a broader, diverse movement of survivors who shared a common thread of pain, loss, stigma, and ineffectively addressed trauma experienced in various degrees and different times throughout the epidemic. Over the past three years, in six major urban centers across the U.S., the Project has organized local leaders to plan local town hall summits and other events in order to reunite and mobilize survivors.

This REUNION PROJECT mobilization helped expand a deeper insight into the diverse individual and community perspectives of survivorship, and led us to believe a national meeting should be convened to assess, deliberate, debate, and prioritize the needs of survivors of HIV nationally, and begin a democratic process to solve those issues.

For the first time, the National Roundtable Forum, a community-led, diverse coalition of advocates who are survivors of HIV from across the U.S., gathered March 30–31, 2018 at the Annenberg Center for Health Sciences in Rancho Mirage, California. Over the course of one-and-one-half days more than 50 advocates convened to develop a national HIV survivorship advocacy agenda.

The main objective of the Roundtable Forum was to come to a consensus regarding a Coalition of Survivorship,¹ and to begin a process to build a sustainable and powerful movement.

THE REUNION PROJECT (TRP) National Committee organized the idea, process, and logistics for the forum. They formed a diverse and well-known assembly of survivor leaders from across the country to make up the participant invitation committee. A deliberate grassroots process was used to invite a sampling of a broad array of survivors of HIV. Participants included long-term survivors of HIV, survivors who perinatally-acquired HIV, caregivers who are HIV-negative, and other survivor expert opinion leaders. Participant diversity also reflected the diversity of the U.S. epidemic: racial, ethnic, gender, sexual orientation, age, and serostatus. Region, profession, skills, and local and national advocacy leadership were also important considerations for invitation.

A second committee of diverse survivor experts known for their work in HIV leadership, advocacy, and policy positions were invited to plan and organize the full meeting including the program content, agenda, speakers and presenters. The committee assisted the TRP National Committee in the collection of background articles, papers, and fact sheets for participants to read prior to the forum. The TRP National Committee solicited two well-known HIV meeting facilitators to organize the agenda, plan each session and exercise, and facilitate the Roundtable.

This report summarizes the main findings of this meeting and the methods used.

THE ROUNDTABLE

Facilitators **Vanessa Johnson** and **Mike Shriver** led the Roundtable and used a combination of group discussions, presentations, and exercises to explore the issues facing long-term survivors of HIV, and to identify some of the unmet needs for this population, with creation of actionable items at its conclusion.



Vanessa Johnson and Mike Shriver

An icebreaker exercise began with a timeline highlighting significant events from the HIV epidemic, from beginning to present day, which was posted on a wall. Participants were asked to place different colored dots along the timeline indicating times in their lives such as when they were diagnosed or first heard about HIV, or when they realized they would survive. In the discussion that followed they were asked what stuck out for them, or what they noticed most about the dots on the board.

One person mourned the networks of people living with HIV (PLHIV) that are now gone.

“Support groups where you feel loved, and other rooms where you get pissed off and change the world.”

Others commented on how difficult it was in the past.

“We got our handicapped placard and a massage, but there wasn’t any treatment.”

“In our darkest times is when we started doing our work—The Denver Principles, PWA empowerment.”



Timeline icebreaker exercise

WHO WE ARE

There have been a number of different definitions to describe long-term survivors over the course of the epidemic. In the mid 1980s, when median survival time was 18–20 months, a long-term survivor was someone who survived three years post-diagnosis. In the '90s it was sometimes used to refer to long-term non-progressors. Today the definition most commonly used is those individuals who were diagnosed with HIV before 1996 and the advent of protease inhibitors and effective combination therapy—and have survived.

The group spent part of the first day deliberating the definition of what constitutes a long-term survivor. An example was provided for discussion:

Long-term survivors still alive from the early days of the epidemic are included in the majority of people living with HIV over 50 years old. Long-term survivors who perinatally acquired HIV are young adults who have been living with HIV since birth. Other people living with HIV for shorter periods of time, and HIV negative caregivers and family members who have experienced untold loss, are survivors of HIV in their own right. Every survivor group and every individual has the right to claim survivorship, each has unique circumstances that need to be addressed, and all share complex trauma from the loss and pain of HIV.

There was some discussion about whether or not HIV-negative individuals should be included in the definition, and people who are more recently diagnosed. Participants did finally agree that:

- **The definition of long-term survivor is less important**—“the reason why we come together is what matters.”
- **Self-determination**—survival is personal and therefore determined by the person who feels they have experienced it, so the definition is inclusive of anyone who has survived. Yet determining long-term survival is important because of the unique issues facing those who have lived multiple years with HIV/AIDS.

As more than one participant pointed out, HIV is not the first or only thing they have had to survive, some have survived homelessness, multiple sexual violence, family rejection, financial instability—and often this was all before they became HIV-positive. So the word survivor can become “really loaded” for some individuals.

“There is power in being in a room with people of shared experiences. Negative, positive, to share those stories, because there is such nobility in those stories. In the sharing of stories we lift each other up.”

—ROUNDTABLE PARTICIPANT

THE FOUR THEMES, OR “BUCKETS”

THE REUNION PROJECT planning committee spent weeks discussing a variety of issue themes survivors of HIV across the country have noted and discussed in town hall summits. Since the Roundtable was a day and a half, the themes were characterized, collated, and divided into four main themes, or “buckets,” to explore:



Research



Programs



Community Building



Advocacy

Eight roundtable participants were asked in advance to present on a model program in their community, two within each of the four main buckets. Participants then broke into smaller groups to expand on each area, and reported back to the larger group. The eight presenters and topics were:



Brown

Arzah

Zinman

Chung

Brennan-Ing

Misrok

De Hoyos

Sharp

1. Isolation, Stigma and Shame

Gina Brown, Southern AIDS Coalition, New Orleans, LA

2. Services for women living with HIV

Tranisha Arzah, BABES Network-YWCA, Seattle, WA

3. Services for LGBT Seniors

Heshie Zinman, Elder Initiative, Philadelphia, PA

4. Positively Trans, resources for people of trans experience who are HIV-positive

Cecilia Chung, Transgender Law Center, Oakland, CA

5. Research on Older Adults with HIV

Mark Brennan-Ing, Brookdale Center, Hunter College, NY

6. Employment services for people living with HIV

Mark Misrok, National Working Positive Coalition, New York City

7. HIV 50+ Strong and Healthy, capacity building, elder HIV-positive training

Fernando De Hoyos, NMAC, Washington, D.C.

8. HIV & Aging Working Group of the Long-Term Care Coordinating Committee at San Francisco Department of Aging and Adult Services

Matt Sharp, Berkeley, CA

Key terms that were used during the discussion that followed included:

Stigma, Social Isolation, Mental Health, Community-inclusive, Community-specific, Community-driven, Visibility, Connection, Ownership, Trauma, Thriving, Surviving, Invisibility, Employment, “No One Left Behind”, ACT UP/Gray Panthers, Advocacy (many iterations), The South, Engagement, Relevance, Funding, Self-determination, Housing, Cure, Allies.

Common themes and stand-out issues emerged under each of the four buckets:



RESEARCH

Disparity—across communities, about communities, in technology transfer, methodologies/data procurement, compensation.

Practicality—about lived experiences, about lives, about communities regardless of denominator, technology transfer, aging, co-morbidities.

Standout issues: The South, Women, Long-term impact of therapies, Trauma, Mental Health, Biological “early aging,” Inflammation, Co-morbidities in the era of viral control, Rapid dissemination



PROGRAMS

Practicality—System-based programs (Navigation, Employment, Goal-oriented,) and Individual/Community-based (Address Isolation and Well-being, Peer-to-peer) and State-of-the-art (technological, rapid dissemination and replicability)

Overarching issues of access and accessibility, awareness, skills and support, competence (cultural- and community-humility).

Standout issues: Mental Health and Well-being, Employment, Economic Justice, Community-based, Expanding partnerships and stakeholder engagement



COMMUNITY BUILDING

Practicality—Social and Community Organizing, Networks, Across and Inter-generational, Expanding the partnerships, Justice

Focus on bringing us together, formally and informally.

Standout issues: Creating safe spaces, Building our own community, Reaching LTS in rural areas, Better understanding the role and power of PLHIV networks, Analysis of power and privilege within wider LTS community, Working with Aging Service communities to integrate best practices, Better representation of youth and those who perinatally-acquired HIV



ADVOCACY

The manner in which and the vehicle we use to accomplish these goals (Research, Programs, Community-building).

The twist on advocacy is self-care, community-care.

Standout issues: Housing, Mental health, Long-term consequences of medications, Dementia/cognitive issues, Job training, Addressing needs of women, esp. women of color, and trans people including binary and non-binary individuals, Meaningful Involvement of People living with HIV/AIDS (MIPA), Reauthorization of Older Americans Act, Protecting Social Security, Medicaid, Medicare, Caregiving/Direct Care Workers

Several participants pointed out the importance of using people-first language (for example some of the language used in the welcome packet for the meeting could have been more inclusive, such as “vertical transmission” instead of “Prevention of Mother-to-Child Transmission (PMCT);” or “survivors who contracted HIV,” instead of “HIV-infected.”

Conversations during the meeting became heated at times, but participants were generally able to work through them as a group. As one person stated there were a diverse number of perspectives, but still ways to find commonality. Another participant remarked that there is “great difficulty in diversity, but it’s required in order to last. We need diversity, it’s okay to argue; you don’t have to see eye to eye in the beginning, as long as you have something you agree on in the end.”

DAY TWO

On day two participants were asked to share how the previous day was for them in a few short words; some said it was “challenging and demanding,” others described it as a “family reunion.”

“Safe. Respectful.”

“Authentic. Comfortable.”

“Amazing, inspired. Scared. [We have a] big path ahead of us. But we can do it.”

“Lonely. Alone. Couldn’t shake the exercise. If I can, [I want to] be intentional about not being lonely.”

“Community here is really amazing. Old friends. New friends.”

“Need to not pretty things up; not lose the reality. I am both broken and brilliant, I don’t want to dance for an outside audience, and that’s my fear when I do this work.”

“Honored to be in the room with others. This is a movement of purpose.”

“[There is a] sense of accountability in the room, a community of people with HIV more broadly than is typical in these kinds of meetings.”

MEETING OUTCOMES

THE REUNION PROJECT National Committee agreed to follow through on four main actionable items, and several Roundtable participants volunteered to serve on sub-committees to work on these action items. They include:

Producing data/document—in the form of a meeting report or summary

Base-building—creating a database for an HIV survivorship coalition

Timeline project—building out the timeline started during the icebreaker to include events significant for long-term survivors; disseminate widely

Submit an abstract on long-term survivors to 2018 United States Conference on AIDS (USCA); and help plan a **reception for long-term survivors** at 2018 USCA

EVALUATION RESULTS

Results from the meeting evaluations showed that **63% of participants would apply the information they learned** at the meeting when they got back home. **Eighty percent said they are interested in following the developments of THE REUNION PROJECT**, and in playing an active role in supporting the **development of a national agenda for long-term survivors**.

CONCLUSION

The needs and priorities of survivors of HIV are many and varied, but there is strength in diversity and in coming together to share our stories. Woven through these heroic stories of survival is a common thread of pain, trauma, healing, and overcoming challenges and obstacles while working toward a common goal. A strong coalition of survivors with a single voice and clear message is desperately needed to advance the needs of survivors, as we continue to battle the long-term effects of medications, isolation, post-traumatic stress disorder, stigma, aging, and co-morbidities, to name a few. THE REUNION PROJECT National Roundtable Forum was the first attempt to assess a nation of survivors, and while not meant to be a full representation of all survivors, serves as the foundation as we move toward building a coalition that speaks for all of us who have survived, and are living, the HIV epidemic.

“There is a relationship between those who manage their stigma and surviving.”

—ROUNDTABLE PARTICIPANT

- [i] Long-term survivors still standing from the early days of the epidemic are among the group of elder survivors, some who became infected before HIV was identified; younger adults who perinatally-acquired HIV, before great strides were made in the prevention of mother-to-child transmission, have grown into young adult long-term survivors; other people diagnosed with HIV/AIDS after effective treatments became available in the mid '90s, have lived up to twenty years with HIV, a significant amount of time; allies in the fight who are HIV-negative—providers, caregivers, advocates, activists, family members, and partners—are often less considered as survivors simply because they are not HIV-positive.

ABOUT THIS REPORT'S AUTHORS



Jeff Berry has been with Test Positive Aware Network (TPAN) and POSITIVELY AWARE magazine since 1992, and has served as editor since 2005. POSITIVELY AWARE is the leading national HIV/AIDS treatment publication published by a not-for-profit AIDS service organization (TPAN) in Chicago.

Berry is co-founder of THE REUNION PROJECT, a grassroots movement to advance the causes and raise awareness around the issues facing long-term survivors of HIV.



Matt Sharp has spent the majority of his adult life fighting HIV/AIDS. A thirty-year long-term survivor, activist, community organizer, writer and educator he now resides in Berkeley, California. Drawing on his vast experience in HIV advocacy and education, he is an HIV/AIDS independent consultant today.

He is helping to shape a national movement of long-term survivors of HIV/AIDS with THE REUNION PROJECT, and helped lead a recent national Roundtable Forum for survivors of HIV/AIDS. His evidence-based report, "The Unintended Consequences of AIDS Survival" was released on World AIDS Day 2016 to critical praise.

CONTACT

To contact the authors email reunionproject@tpan.com.

To learn more about THE REUNION PROJECT go to tpan.com/reunion-project.

THE REUNION PROJECT National Steering Committee includes
Chris Bartlett, Philadelphia; Jeff Berry, Chicago; Gregg Cassin, San Francisco;
Waheedah Shabazz-El, Philadelphia; Matt Sharp, San Francisco;
Louis Spraggins, Chicago; Jeff Taylor, Palm Springs, CA.

THE REUNION PROJECT National Roundtable was made possible
by support from Gilead Sciences, Bristol-Myers Squibb, Merck,
Walgreens, TPAN, and Eisenhower Health, and hosted by
HIV+Aging Research Project-PS (HARP-PS).

