BUILDING A COMMUNITY COLLABORATIVE HCV MOVEMENT

CLIFTON GARMON
CHIEF OF STAFF, VOCAL-NY
BUILDING POWER THROUGH ADVOCACY?

• **WHAT IS ADVOCACY?** Public support for or recommendation of a particular cause or policy.

• **WHY DO WE ADVOCATE?**

• **WHAT IS ORGANIZING VS ADVOCACY?**
THINGS WE CONSIDERED FIRST . . .

• RECOGNIZED OUR POLITICAL LANDSCAPE (FEDERAL, STATE, AND LOCAL)
• TAILORED OUR MESSAGE TO APPROPRIATE AUDIENCES
• UTILIZED THE MEDIA & SHIFTED THE NARRATIVE (CUTTING THE ISSUE & STORYTELLING)
• KNEW OUR ALLIES, OUR OPPONENTS, & OUR OPPONENTS’ OPPONENTS
• BUILT & LEVERAGED RELATIONSHIPS WITH TRADITIONAL & NON-TRADITIONAL ALLIES
CONSTRUCTING A FOUNDATION

• COMMUNITY ORGS PARTNERED WITH NYS/C HEALTH DEPARTMENTS TO CONSIDER AND BUILD CONSENSUS ON STATEWIDE OPPORTUNITY FOR HCV ELIMINATION.

• 94 STAKEHOLDERS CAME TOGETHER IN WORKING GROUPS TO DEVELOPED RECOMMENDATIONS TO INFORM A STATEWIDE HCV ELIMINATION PLAN.

• FIVE WORKING GROUPS WERE ESTABLISHED: 1) PREVENTION, 2) TESTING & LINKAGE, 3) CARE & TREATMENT ACCESS, 4) DATA, SURVEILLANCE & METRICS, 5) SOCIAL DETERMINANTS OF HEALTH.
COMING TO A CONSENSUS

1. **ENHANCE HCV PREVENTION, TESTING AND LINKAGE TO CARE SERVICES FOR PEOPLE WHO INJECT DRUGS, PEOPLE WHO ARE INCARCERATED, MEN WHO HAVE SEX WITH MEN AND OTHER POPULATIONS DISPROPORTIONATELY IMPACTED BY HCV INFECTION.**

2. **EXPAND HCV SCREENING AND TESTING TO IDENTIFY PEOPLE LIVING WITH HCV WHO ARE UNAWARE OF THEIR STATUS AND LINK THEM TO CARE.**

3. **PROVIDE ACCESS TO CLINICALLY APPROPRIATE AND AFFORDABLE HCV TREATMENT WITHOUT RESTRICTIONS AND ENSURE THE AVAILABILITY OF NECESSARY SUPPORTIVE SERVICES FOR ALL NEW YORKERS LIVING WITH HCV.**

4. **ENHANCE NYS HCV SURVEILLANCE, SET AND TRACK HCV ELIMINATION TARGETS AND MAKE INFORMATION AVAILABLE TO THE PUBLIC.**

5. **COMMIT NYS GOVERNMENT AND ELECTED OFFICIALS, PUBLIC HEALTH PROFESSIONALS, HCV EXPERTS AND INDUSTRY PARTNERS TO LEADERSHIP AND OWNERSHIP OF THE NYS PLAN TO ELIMINATE HCV ALONGSIDE COMMUNITY MEMBERS LIVING WITH AND AFFECTED BY HCV.**
OUR COLLECTIVE CALL TO ACTION

New York State faces a growing Hepatitis C epidemic with a rising death toll. Given the availability of new highly effective, well-tolerated curative treatments, we can no longer settle for a low cure rate that perpetuates the high fiscal and human costs of inaction.

The committee that organized the NYS Hepatitis C Elimination Summit, along with the other providers, community based organizations and individuals living with and affected by Hepatitis C that sign this consensus statement, call on Governor Andrew Cuomo, the NYS legislature, and industry partners to make a joint commitment to Hepatitis C elimination, and for appointment of a formal NYS Hepatitis C elimination task force.
FRUITS OF OUR LABOR

✓ MARCH, 2018: GOVERNOR CUOMO MADE A PUBLIC COMMITMENT TO ELIMINATING HEPATITIS C IN NYS

✓ JULY, 2018: GOVERNOR CUOMO COMMITTED TO ESTABLISHING A HCV ELIMINATION TASK FORCE, AND COMMITTED TO MAKING MUCH NEEDED REGULATORY CHANGES.

✓ FINAL NYS FY 19 BUDGET INCLUDES $5 MILLION IN NEW FUNDING FOR HEPATITIS C ($10M OVER 2 YEARS)

✓ THE NYS HCV ELIMINATION TASK FORCE DRAFTED AN ELIMINATION PLAN THAT WILL SOON BE RELEASED
WHAT KIND OF ADVOCATE ARE YOU?

COMMUNITY MEMBER/LEADER

1) Use Your People Power, 2) Contribute Your Unique Experience & Skill Set (E.G. Directly Impacted Person, Medical Professional, Graphic Designer), 3) Use Your Constituent Power, 4) Share Your Story, 5) Join A Group That’s Taking Action, 6) Show Up!

COMMUNITY BASED ORGANIZATION

1) Join A Coalition, 2) Link Your Participants To People Organizing Around An Issue, 3) Provide Your Perspective, 4) LOBBY, LOBBY, LOBBY (Or Partner W/Grassroots Lobby Groups), 5) Testify At Public Hearings On The Issue, 6) Assist Clients/Participants W/Advocacy Efforts (E.G. Op-eds, Lobbying), 7) Get Activated!

GOVERNMENT EMPLOYEE

1) Provide Updated Data/Info To CBOs, 2) Be A Bridge Between CBOs & Community Leaders, 3) Speak Up About Gaps That Exist In Services, (Etc.) During Public Testimonies Or Legislative/Budget Briefings, 4) Talk About Improvements That Were Made Or Goals That Were Reached Due To Resources Made Available (Likely Because Of Previous Advocacy Efforts), 5) Attend Community Forums/Events To Stay In The Know/Provide Your Professional Insight
WHAT LEVEL ARE YOU ADVOCATING ON?

LOCAL
1) Fund Local Initiatives, 2) Utilize Press, 3) Partner W/Gov. Agency Or CBOs

STATE
1) Join A Campaign, 2) Grassroots Lobby, 3) Identify Champions, 4) Participate In Advocacy Days, 5) Make An Ask(s) To Stand Behind, 6) Get Directly Impacted Folks Involved

FEDERAL
1) Join A Group W/An Advocacy Budget, 2) Go Digital W/Your Campaign, 3) MAKE SOME NOISE!, 4) Use The Media To Talk About Your Issue, 5) If Possible, Lobby In D.C.

INSTITUTIONAL (E.G. HOSPITAL, UNIVERSITY, YOUR AGENCY)
THANK YOU!