

# North Texas Prostate Cancer Coalition

Program Review, October 21, 2009

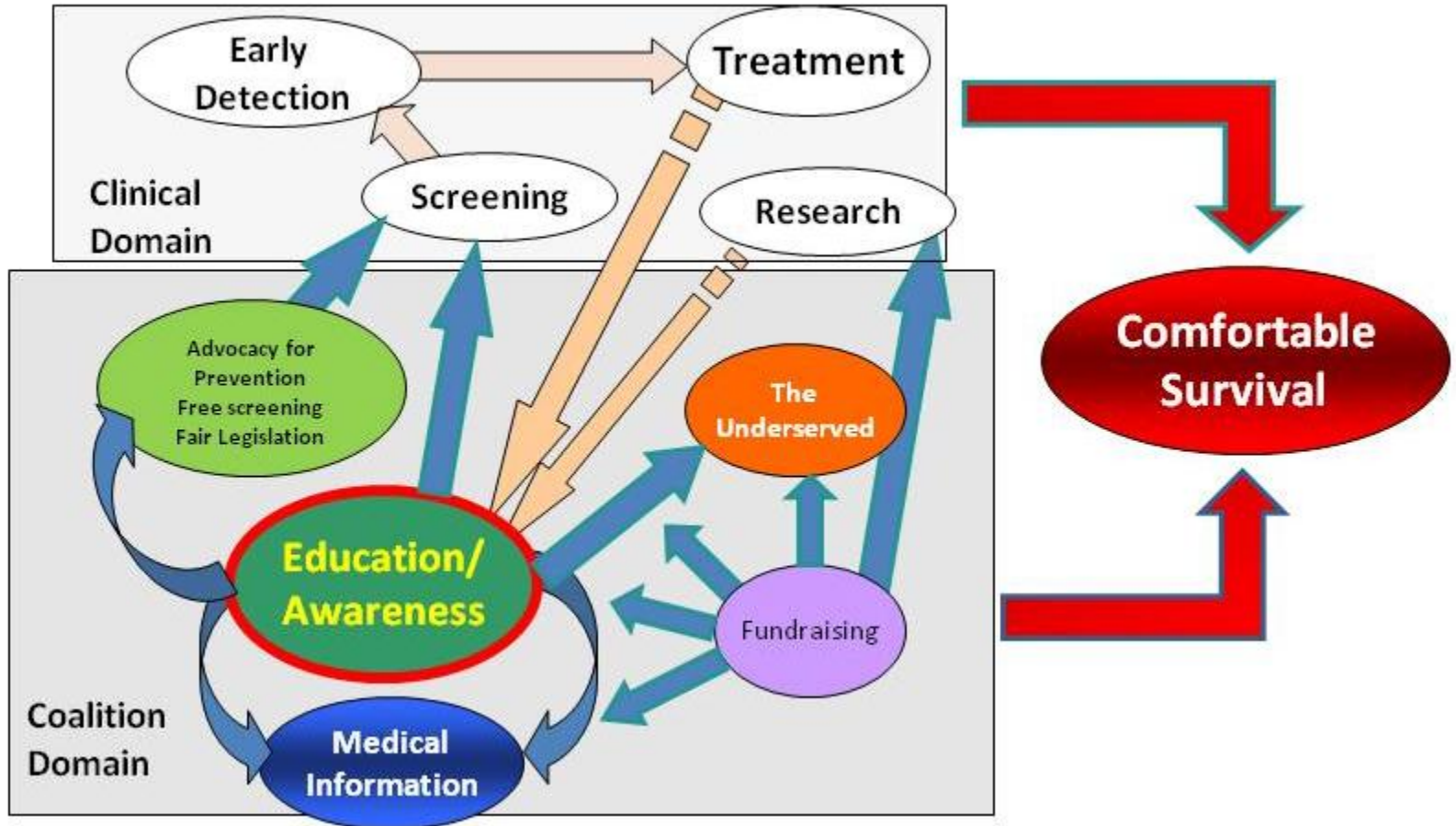


**Together For Good Health**

# NTXPCC – Agenda

- **Opening Remarks**
  - February Meeting, Summary
  - The Coalition
  - Coalition Programs
- **Program Review**
  - Speakers' Bureau
  - “Working Groups”
  - Free Screening Support
  - Website
  - Combined Speakers
- **Break**
- **Report on NASPCC Meeting**
- **Hot Items**
  - How do we increase meeting attendance?
  - Recruiting Physicians as Speakers

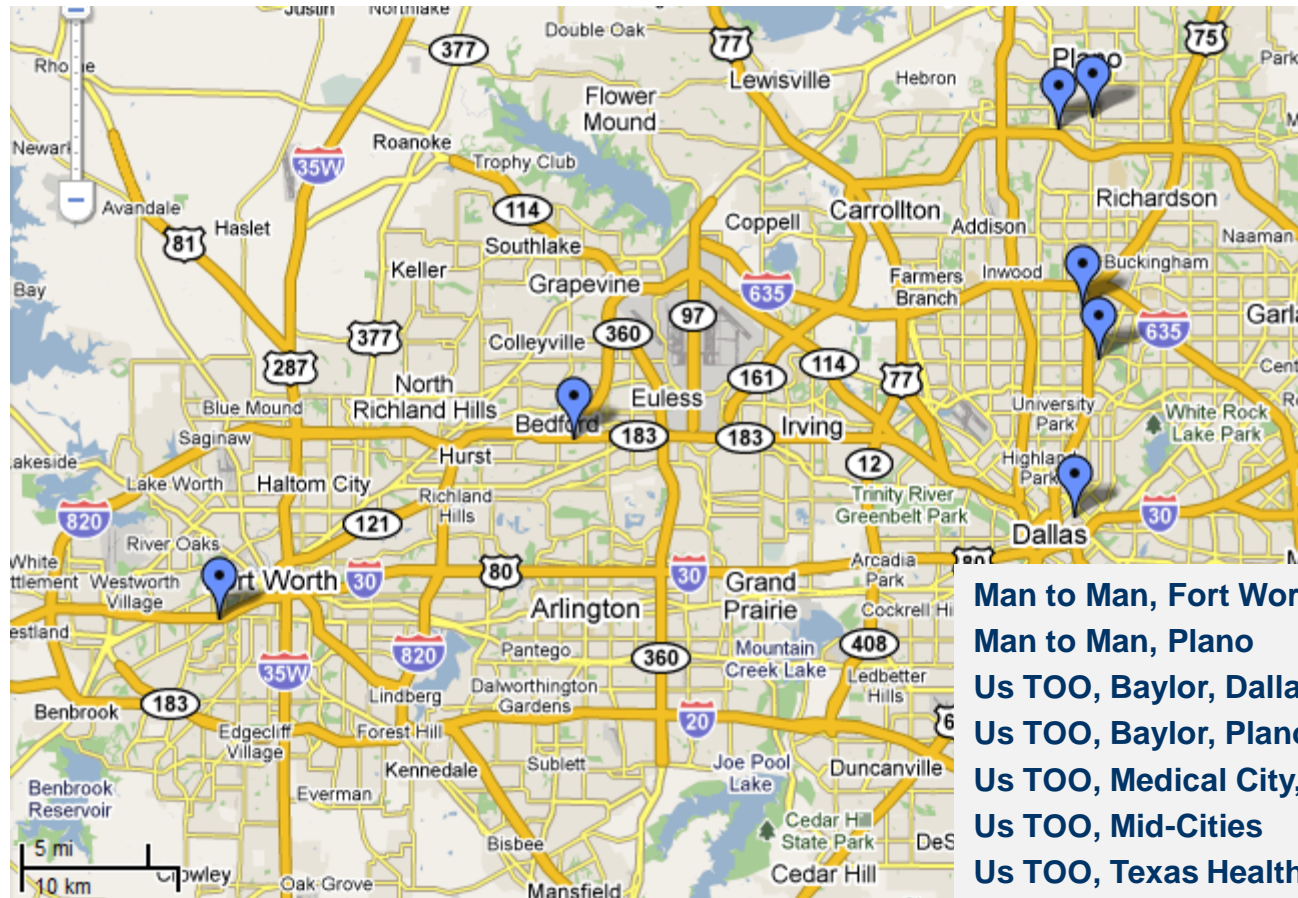
# Coalition Intention Plan



## February 2009 Meeting, Summary

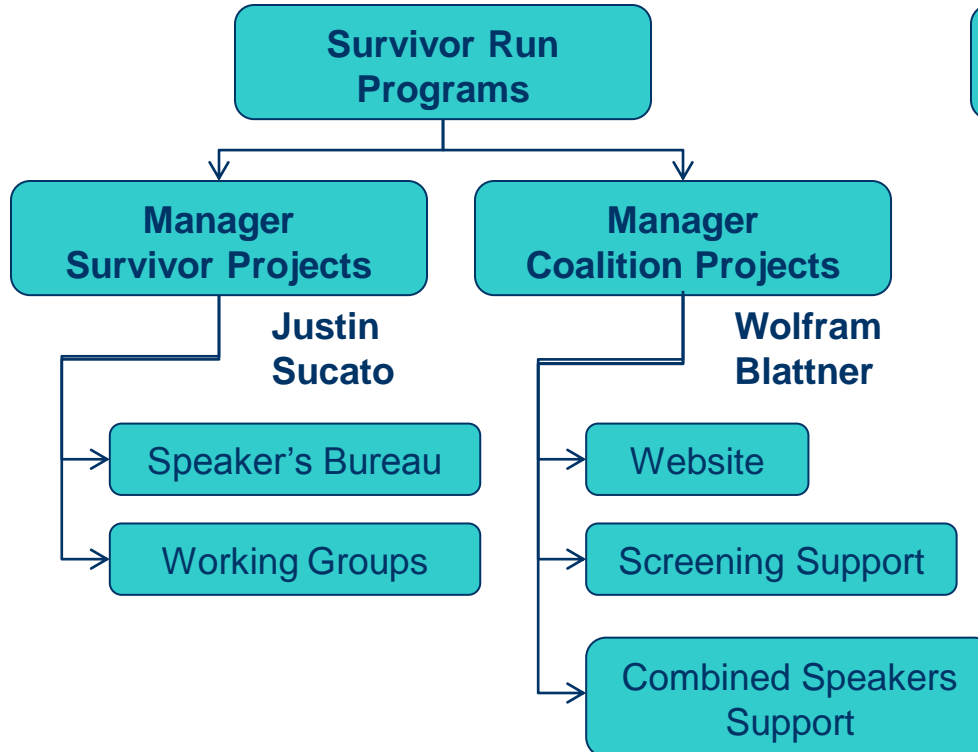
- As in many successful endeavors **we want to start small**, proceed cautiously with majority approval on major programs and projects.
- We want to review the three selected project plans and ask for a **vote to proceed with implementation** on each project.
- The project managers who will conduct the implementation process **will address the concerns you have listed** and communicate with you **to be certain they are reconciled.**

# NTXPCC - Current Coalition



- Man to Man, Fort Worth**
- Man to Man, Plano**
- Us TOO, Baylor, Dallas**
- Us TOO, Baylor, Plano**
- Us TOO, Medical City, Dallas**
- Us TOO, Mid-Cities**
- Us TOO, Texas Health Presbyterian, Dallas**

# NTXPCC Organization



## Support Group Leaders/Contacts

Polly Candela  
 Angela Clark  
 Joanne Cortez  
 Tom Dillon  
 Emily Gentry  
 Gene Hogan  
 Jaren Smith  
 Jan Tichenor  
 Gayle Wilkins  
 Bob Williams

## Medical Advisors

Pete LaNasa, MD  
 Trey Moore, MD  
 Matt Shuford, MD

# Coalition Plans

- **Non-Profit**
  - We need to incorporate and go non-profit in 2010 or before
  - Will file for a non-profit organization with the State next week (required step towards 501(c)(3))
  - File for 501(c)(3) with IRS afterwards; requires acceptance of bylaws
- **Statewide Interest Groups**
  - Identified some of them
  - Statewide plans TBD
- **NTXPCC**
  - NTXPCC will stay as Metroplex Coalition



# Programs



- \* **Speakers' Bureau** – Volunteer Long Term Survivor (LTS) members addressing healthy men at the various area men's groups
  - “Working groups”** – Men in like stages of PC meeting in roundtable discussion format to share information, knowledge and experience
  - \* **Free Screening Support** initiatives.
- 
- \* **Monthly Meeting Notice/Newsletter (Website)**  
Volunteer LTS listing for dyadic (one to one) support
  - \* **Recognized speakers for combined groups presentations ~**
  - \* **Poster Program ~**
- \* **Funding necessary**



# Speakers' Bureau

Presenting to Healthy Men on the Importance of Early Detection

## Initial Plan

- **Organization**
- **Equipment**
- **Speaker Training**
- **Correspondence to men's groups**
- **Presentation**





# *"Working Groups"*

## Initial Plan

### Cohort Groups to be formed :

- Newly Diagnosed
- Recurring after initial or salvage treatments
- Recurring after hormonal treatments
- Those with documented metastasis



## Screening – Initial Plan: How do We Start?

- Big Programs NOT an option for the Coalition at this time
- **Screening Support**
  - Survivors need to get more involved in supporting screenings
    - Volunteering before and during events
    - Assisting in publicizing events
    - Will start with DadFest
- **Coordinate Screenings**
  - Needs Hospital Coordination
  - Dallas Area Hospitals: why not offer screenings throughout year, like Presbyterian at Valentine's, Baylor/P in June\*, Medical City in August, Baylor/D\* in September?
  - Stay away from June\* (DadFest), September (PC Awareness month has smaller screening events)
- **Challenge: Can We Increase Screening Numbers this Year?**

\*) Dates Fixed  
in 2008



# Screening Data, 2009

- **Events**
  - DadFest (TH Presbyterian/Dallas)
  - Men's Health Day, Baylor/Plano
  - Cruisin' for a Cure - Carshow (TH Harris Methodist/Fort Worth)
  - Free Male Health Screening, Medical City/Dallas
  - Free PC Screening, Baylor/Dallas
  - TH Harris HEB/Bedford (November)
- **Requirements**
  - PSA & DRE
  - Some hospitals lowered minimum age requirements to 35 or 40
- **Numbers**
  - **Around 880 men were screened (~10% increase from 2008)**
  - **One hospital reported 8.8% abnormal results**
  - **Did Coalition activity and screening controversy increase awareness?**



# Screening Support - Progress

- **Increased number of volunteers at all events**
- **Increased publicity through website, some flyers**
- **DadFest**
  - (Played screening video by Dr. Fulgham)
- **Men's Health Day, Baylor/Plano**
  - **Presented Early Detection material** (2 sessions)
- **Cruisin' for a Cure**
- **Screening, Medical City/Dallas**
  - **Presented Early Detection material** (2 sessions)
- **Screening, Baylor/Dallas**
- **Texas Health HEB**
  - Now November 21



# Screening Support – 2010 Plan

- **Screening Support**
  - **Can Early Detection material be presented at DadFest, Baylor/Dallas and at HEB?**
  - **Use survivors in screening lane (to answer questions)**
  - **Use flyers for DadFest/Cruisin' for a Cure, distributed by survivors?**
- **Coordinate Screenings**
  - **Medical City/Dallas and Baylor/Dallas screened at the same day this year**  
**Is there a way to change that?**
- **Publicity**
  - **Baylor/Dallas, Medical City, Dallas and TH HEB listed by PCAW**
  - **TH Harris FW?**
- **Challenge: Can We Increase Screening Numbers in 2010?**
  - **Lower budgets for screening?**



# Screening – The Next Step #1 ?

- **NBA Opportunity?**
  - 2009 Screening at Chicago Cubs – NBA interest
  - Information passed out 10 days ago
  - (McEnroe managed to arrange for screenings at US Open)
  - Screening possibility with Mavericks?
- **Tony Romo’s “Tackle Prostate Cancer “**
  - 100,00 to be encouraged to be screened (13 NFL teams)
  - Screening possibility with Cowboys?
- **Zero has contract with Washington Capitals**
  - Screening possibility with Stars?





## Screening – Alternative/Combination ?

“Our local professional hockey team sponsored a weekend for PC. Our local UsTOO had a booth for both nights and the hockey team wore blue helmets which were auctioned off. We were able to sell tickets and received 50% off the cost of the tickets plus all of the proceeds minus expenses of the sale of the helmets in the silent auction.

We hope to do it again this year.”

Lew Musgrove, Nevada



# Screening – The Next Step #2 ?

- **New Screening Program?**
  - Small screening events (churches, clubs, etc.)
  - Couldn't find anybody for a requested screening at a health fair in Mesquite (though short notice, was embarrassing)
  - Some hospitals have policies against outside "screening"
  - Urology association or hospital identifies physicians/nurses for possible screening day
  - Request will be honored if a minimum number of men are signed up before the fair
  - Screening times will be adjusted to number of men signed up
- **Discussion**

# The Other Projects?

- **Combined Speakers**
- **Newsletter (Website)**
- **LTS listing**
- **Poster Program**
  - will come with other program development

**Not Left Out!**

# Combined Speakers? Initial Plan

- **Should be pursued, one event per year?**
  - Different Hospital every year?
- **Local Speaker**
  - Cheaper option to national speaker
  - Doctors' Forum?
- **National Speaker**
  - Will require funding by hosting chapter(s)
  - Dr. Myers last year was a perfect example, except ...
- **Either Options Needs**
  - Adequate Facilities
  - High Advertisement
  - Participation by all chapters/groups

**Local Leaders are  
Major Players for  
Speaker Program**

# Combined Speakers - Progress

## **1<sup>st</sup> Annual Prostate Cancer Survivor Celebration**

- Baylor/Dallas
- Local speaker: Scott Murray
- Attendance ~ 150
- Recognition Awards
- High Coalition visibility

## **Coalition Involvement**

- Very high publicity (internet, local meetings, email)
- Contributed to joined Coalition/Us TOO Baylor exhibition table
- All support groups were represented through leaders and/or survivors

# Combined Speakers

## 2010 Plan

- **Seems that Baylor/Dallas will continue the Annual Survivor Celebration event**
- **National Speaker**
  - Dr. Ian Thompson, UT Health Science Center, San Antonio, has tentatively agreed to come to the Metroplex in 2010
  - Information sent to hospital contacts
  - Should be separate from September Survivor Celebration event
- **Please notify us in time if you are planning to bring in other speakers**
  - We will support

# Website

- **Plenty of Information**
  - Up-to-date
- **Try to stay away from controversial information**
  - Added two medical advisors
- **All events are posted**
  - **Chapter leaders are responsible for correctness of information regarding their respective chapter**
  - Related events are posted as well
- **Additional Website data in Backup**
- **Love to have input / suggestions**
  - Major or minor



# Website – Posting Policy

- **General postings**

- All support group meetings
- Special events by associated or non-associated hospitals (including general cancer program events)
- PC news, unless they are strictly research (may consult advisors, expect advisors to ask me to add/remove if necessary)

- **Fund-raising requests**

- PC Fundraisers by associated organizations
- Selected Regional or National Fundraisers (ACS, Us TOO, ZERO, PC Foundation)

# Website – Denial of Posting Request - proposed

- **Special Events**
  - Health Fair events whose main purpose is the sale of specific products or events where patients sign up for a specific physician
- **Fund-raising requests**
  - Fundraisers for local out-of-state organizations with no direct benefit to local survivors
- **Advertisement-like material for hospitals, physicians or physicians' associations**
- **Discussion**
- **Vote**



# LTS Listing

**Will be contained in NDX Manual**

# Poster Program

- **Coalition Flyer**
  - Distributed at most screening events, some health fairs outside coalition, local meetings, survivor celebration
  - Can Coalition flyers be posted in doctor's offices?
- **Screening Announcement Flyers**
  - KoC, Mesquite Health Fair, Baylor/Plano
- **Funding**
  - Printing capabilities at some of the events
  - Printed on personal printers
- **2010 Plan**
  - Partially outlined in NDX plan
  - Increased involvement in Health Fairs

# NASPCC

## National Alliance of State Prostate Cancer Coalitions

- **Mission Statement**

To provide support to existing state prostate cancer organizations; to facilitate the development of new state prostate cancer organizations; and to serve as a collective and collaborative voice to make prostate cancer a national health care priority.

- **Currently 30 State Coalitions (plus DC)**

- Including Texas (TPCC)
- Some of the “State Coalitions” are single groups
- Membership definitions within NASPCC will be re-defined



# NASPPC Meeting – Chicago

## (Oct 10-11)

- **Main emphasis on assisting to strengthen State Coalitions**
- **Minutes mailed to NTPCC leadership**
- **Guest Speakers**
  - **Alan Partin, MD (Johns Hopkins)**  
“Novel and Potentially Useful Urine, Tissue & Blood Bio-Markers For Prostate Cancer Detection”
  - **Ian Thompson, MD (UT, San Antonio)**  
“Seeking the Cure for Prostate Cancer: Impatience and Perseverance”
  - **Tom Kirk, CEO, Us TOO International**  
Working Together

# NASPCC – Philosophies/Resolution

- **Support AUA screening guidelines**  
Minimum age 40
- **Pushing for Office of Men’s Health**
- **Passed resolution to increase Federal PCa budget**  
“NASPCC and its members support and request Congress appropriate \$125,000,000 for Congressional Directed Medical Research Programs”



# Open Discussion

- **Meeting attendance**
- **Speakers for local meetings**
- **Other?**

# North Texas Prostate Cancer Coalition



TOGETHER FOR GOOD HEALTH

# Program Review, Oct. 2009

## Back-Up



**February 2009**

# Listing - Men's Clubs

**Rotary Club**  
**Knights of Columbus**  
**Dallas Athletic Club**  
**Men's Church Groups**  
**VA Hospital**  
**Senior Centers**  
**YMCA**  
**Kiwanis Clubs**  
**Health Clubs**  
**Municipal Organizations**  
**Health Concious Business Organizations**  
**Medical Institutions Addressing Men's Health**  
**Others ...**



# Screening – What do we have to offer?

- **Within our Current Coalition (2009 data)**
  - Dad Fest: Texas Health Presbyterian; June
  - Free Screening Day, Baylor/Plano, June 20
  - Cowtown Cruisin' for a Cure: Texas Health Harris/Texas Oncology, Sept. 19
  - Free Screening Day, Baylor/Dallas, September 26 **2008: Total >700**
  - Free Screening Day, Medical City, September 26 **2009:**
- **Website**
  - Advertise events, list all screening events that we are aware of
  - Includes East Texas Medical Center and Methodist Medical Center, Dallas
  - **Will not be read by men who should be screened!**

**This is not  
Sufficient**



# Screening – The Next Step

- **New Screening Programs**
  - Involve Funds & Hospital Participation
  - We need to develop a plan, together with the Hospital Leaders
  - Main responsibility will stay with hospitals
- **Learn More**
  - Other screening programs
  - Sponsors



# Non-Profit

- **Sponsors Expect**
  - Website ✓
  - 501(c)(3)
  - Functional organization (awareness, screening data, etc.)
- **501(c)(3) requirements**
  - an organization with members and a leadership
  - a documentation (by-laws) on the organization
  - conflict of interest disclaimer
  - 28 page application that may require additional documents
  - statement of income and expenses
  - \$300 application fee if our projected income is less than \$5,000 (otherwise \$750)
  - funding for application fee; we should be able to get free legal help from survivors

## 2009 Progress

# Website – 2009 Enhancements

- **Appearance**
  - Added Logo
  - Changed Background Format
  - Added graphics
- **Content**
  - Added News Archive (by category)
  - Articles written by local physicians (1 at this time, 1 requested)
  - Coverage of some special events
  - Updated existing information (ongoing)

# Website – 2009 Traffic

**Total Hits:** 1,214  
 - 1/1/09-9/30/09  
 - Does not include webmaster

**Average:** 4.2/Day

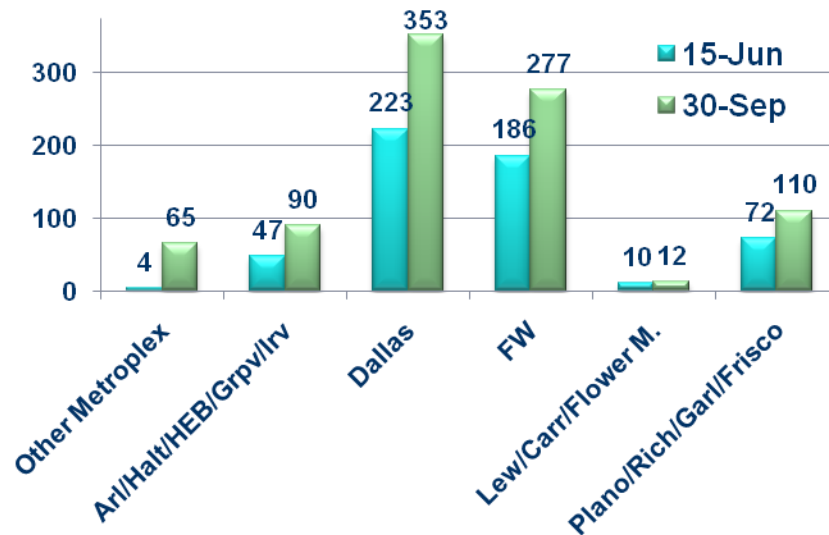
**#US Cities:** 179

**#US States:** 38  
 - Includes DC

**Texas:** 84%

**Metroplex:** 75%

**Total Hits, 1/1/09-9/30/09**



- Strong activity in Dallas, Ft. Worth