

Register

A joint project of the Sylvester Comprehensive Cancer Ctr
and the Florida Department of Health

Division of Cancer Prevention and Control

Volume 44 – July, 2009



NAACCR 2009 Conference

June 13-19, 2009

The Westin San Diego - San Diego, California

**“Charting the Course to
a New World in Cancer Surveillance”**

It is with great pride and pleasure that I share with you the highlights of the 2009 Meeting of the North American Association of Central Cancer Registries in San Diego. This year the California Cancer Registry hosted the NAACCR Annual Meeting June 13th through 19th. San Diego is a beautiful city with even better weather. The days never got above 80 degrees while the evenings were in the 60s. San Diego has much to offer visitors including the historic Gaslamp Quarter, USS Midway aircraft carrier, beautiful Catalina Island, the world famous San Diego Zoo and some excellent Mexican food which I personally partook in at Old Towne.

Florida was well represented. Eight of our abstracts were accepted for oral presentations using the fantastic data our Florida Registrars work so diligently to provide us. In addition, Florida had two posters ac-

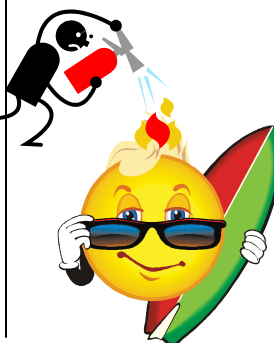
cepted, of which the one by Dr. David Lee received second place honors. Below are the abstracts for these presentations.

I want to thank each and every one of you for your continued diligence in case finding and abstracting the data. Without all your efforts, we would not be able to represent Florida so prominently on the national level.

THANK YOU,
Gary M. Levin, BA, CTR

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SUMMER



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Florida was well represented with eight oral presentations and two posters. The abstracts accepted for oral presentations were as follows: **"NATIONAL DEATH INDEX LINKAGE & RESOLVING DUPLICATE CANCER CASES: NY & FL EXPERIENCE"** presented by Brad Wohler; Recinda Sherman presented **"RESIDENTIAL MOVEMENT BETWEEN CANCER DIAGNOSIS & DEATH"** and **"ASSESSING QUALITY OF GEO-CODED DATA"**; **"FLORIDA BLADDER CANCER CLUSTERS: IDENTIFICATION OF POPULATIONS AT RISK"** presented by Dr. Jill MacKinnon; **"IMPLICATIONS OF MORTALITY ASCERTAINMENT USING THE NATIONAL DEATH INDEX AND SOCIAL SECURITY DEATH INDEX ON SURVIVAL ANALYSIS"** presented by Dr. Monique Hernandez; **"CANCER INCIDENCE AND MORTALITY AMONG ADOLESCENCE AND YOUNG ADULTS AGE 15-39 IN FLORIDA"** presented by Dr. Youjie Huang of the Florida Department of Health; **"THE PAPER-LESS OFFICE: AUTOMATING QUALITY CONTROL ACTIVITIES IN FLORIDA"** presented by Mayra Alvarez; and **"THE HISPANIC PARADOX AT THE CANCER REGISTRY LEVEL"** presented by Dr. Paulo Pinheiro. The two posters accepted were as follows: **"SPATIAL MODELING OF PANCREATIC CANCER (PC) AND PROXIMITY TO ARSENIC-CONTAMINATED WELL SITES"** by Dr. David Lee and **"DISPARITIES IN SURVIVAL AMONG WOMEN WITH INVASIVE CERVICAL CANCER: A PROBLEM OF ACCESS TO CARE"** by Dr. Lora Fleming.

Abstracts of Oral presentations:

NATIONAL DEATH INDEX LINKAGE & RESOLVING DUPLICATE CANCER CASES: NY & FL EXPERIENCE

Brad Wohler (Florida Cancer Data System, Miami, FL); Baozhen Qiao (New York State Cancer Registry, Albany, NY); Hannah Weir, (CDC, Atlanta, GA)

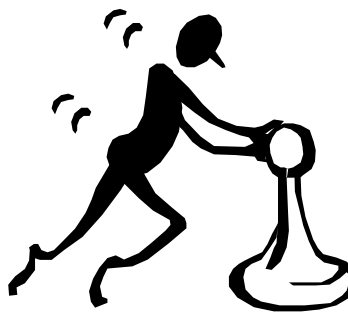
Enhancing data with limited sources has always been a challenge for the incidence based state cancer registries. Currently state cancer registries are required to perform an annual match with the vital statistics of their state for the purpose of finding missing cases and updating vital status; however these results are limited to only those deaths occurring among residents of the reporting state. The National Program of Cancer Registries (NPCR) has successfully negotiated an agreement with the National Death Index (NDI) permitting the state cancer registries to match their records with NDI at no cost to the cancer registries. In addition, this linkage enables the states to share information (except cause of death) garnered through the NDI match to resolve duplicate case reporting between the states. The purpose of this presentation will be to examine the potential of the NDI linkage to resolve duplicate reporting where the cancer patient was diagnosed in one state and died as a resi-



dent in another state. Cancer incidence and mortality data including the NDI results from both the New York and Florida cancer registries will be used to provide insight into the impact of duplicate case reporting. Criterion for resolving duplicates will also be presented for discussion.

RESIDENTIAL MOVEMENT BETWEEN CANCER DIAGNOSIS & DEATH

RL Sherman, G Levin, B Wohler, FCDS, UM, Miami, FL



Background: Social context, such as community socioeconomic conditions, has a direct effect on health outcomes. The relevance of area-based socioeconomic measures (ABSMs) stems from the application of ecological models which posit that the health of populations and

individuals is influenced by the interaction of biological, environmental, and behavioral factors. ABSMs can help capture the capacity of individuals in a community to access and benefit from health resources. In general, studies have shown that individuals living in poor areas have worse health outcomes compared with individuals living in affluent areas. However, due to inherent limitations, (including extensive lag time between exposure and diagnosis and the high level of residential movement), the argument that sick people move to impoverished neighborhoods cannot be ruled out without including a historical residential history. **Methods:** This study evaluated the difference between Florida cancer patients from their resident address at diagnosis and at death. Cases included all Florida residents diagnosed with cancer from 1981-2006 who matched a Florida mortality record from 1995-2006. About 1% of the cases and 31% of the deaths had invalid geocodes and were excluded from analysis. **Results:** About 6% of cases geocoded at both time points moved to a different county after diagnosis, and 20% moved to a different census tract. Of those that moved to a different tract, 87% moved to a tract with same poverty level. Blacks, Hispanics, those with more advanced stage disease, and those dying in a hospital had slightly higher percentages of cases moving into more affluent communities after diagnosis. **Implications:** While lack of residential history is a limitation for analysis on ABSMs using central cancer registry data, it is unlikely to render such analysis invalid

ASSESSING QUALITY OF GEOCODED DATA

RL Sherman, M Hernandez, J Button, D Powell, B Wohler, FCDS, UM, Miami, FL

Background: Florida Cancer Data System (FCDS) uses an outside vendor to geocode registry data. FCDS identified significant errors in the geocoded

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data. To select a new vendor, FCDS assessed the data quality of potential geocoding vendors prior to signing a contract as well as the quality of re-geocoded cases returned from the new vendor. **Methods:** The vendors were tested with 2,000, randomly selected (25% from rural counties), "Gold Standard" cases. Half of the test file was cancer cases geocoded to the block group level in-house using the internet tool available from the US Census. The remaining test cases were addresses of wells geocoded by the Florida Department of Environmental Health using handheld GPS units. Quality was assessed by comparing the returned data against the "Gold Standard". After final vendor selection was made, differences in analysis results using the old and new data were assessed and data quality checks were developed for use by FCDS. **Results:** Results from tested vendors were similar; therefore, selection was ultimately based on customer service. After re-geocoding the FCDS database, the data were less complete (13% vs <1%) but more accurate than previous data. Analysis on re-geocoded data showed markedly different locations of clusters from prior analysis. Analysis on community level characteristics was less sensitive to poorly geocoded data. Estimated ORs based on old data were supported and strengthened using improved data. **Implications:** Beyond merely stating the percent of ungeocodable, there is no standard method of presenting the quality of the underlying geocoded data. Due to the existing structure of the NAACCR layout and other registry standards, NAACCR registries are in a unique position to develop guidelines for evaluating and presenting geocoded data quality to researchers and for publication.

FLORIDA BLADDER CANCER CLUSTERS: IDENTIFICATION OF POPULATIONS AT RISK

AM Neider, JA MacKinnon, LE Fleming, G Kearney, JJ Hu, RL Sherman, Y Huang, DJ Lee, UM, FCDS, Miami, FL

Introduction: Modifiable risk factors for bladder cancer (BC) have been identified (i.e., tobacco and chemical exposure). We sought to identify high-risk areas of BC and risk factors associated with BC clusters by stage in Florida using individual and area-based data. **Methods:** Spatial modeling was applied to both early and advanced BC cases diagnosed between 1998-2002 in Florida (n=23,266) to identify areas with excess cancer risk. Multivariable regression was used to determine if sociodemographic indicators, smoking history, and proximity to known arsenic-contaminated well sites were associated with being diagnosed with BC within a cluster. **Results:** Spatial modeling identified 12 clusters in which approximately 25% of all late-stage BC cases were located. Urban, white patients were more likely to live within an advanced BC cluster. Advanced BC cluster membership was associated with living in close proximity to known arsenic-contaminated drinking water wells. **Conclusions:** There are multiple

areas of BC clusters within Florida. Those within an advanced BC cluster tend to live close to arsenic contaminated wells. Increased evaluation of potentially contaminated well-water within these high-risk areas is warranted. Targeted BC public awareness campaigns, smoking cessation support and targeted screening --should also be considered in communities at increased risk for bladder cancer.

IMPLICATIONS OF MORTALITY ASCERTAINMENT USING THE NATIONAL DEATH INDEX AND SOCIAL SECURITY DEATH INDEX ON SURVIVAL ANALYSIS

MN Hernandez, B Wohler, FCDS, UM, Miami, FL

Mortality ascertainment is an important function of cancer registries as it provides the basis for many epidemiological analyses. While annual linkage to state vital statistics data is the primary source for mortality ascertainment, results are limited to deaths occurring within the state. Incomplete mortality data can have significant affects on the results of survival analysis leading to overestimated rates. A useful method to mitigate these limitations is to link abstracted cases to the National Death Index (NDI) and the Social Security Death Index (SSDI), providing both decedent data for deaths occurring outside the state and supplementing cause of death information. In a recent attempt to support these linkages, the National Program of Cancer Registries (NPCR) has negotiated an agreement with the NDI permitting the state cancer registries to match their records with NDI at no cost. Linkages to the social security death index are currently free of charge. These sources can significantly impact data completeness with regard to vital status and date of death, and in turn, the outcome of epidemiological studies that use the data.

The purpose of this presentation is to analyze the implications of mortality ascertainment through supplemental sources, such as the National Death and Social Security Death Indexes, on survival rate estimations. Specific research questions in this study consider if these linkages significantly change survival rates, and whether use of the Social Security Death Index should be recommended as an additional resource for mortality ascertainment. Results of analysis with and without the use of NDI or SSDI data will be presented.

CANCER INCIDENCE AND MORTALITY AMONG ADOLESCENCE AND YOUNG ADULTS AGE 15-39 IN FLORIDA

Y Huang, T Hylton, Florida Department of Health, FL USA

Background: Although a diagnosis of cancer in adolescence and young adulthood is a relatively rare event, there are special physical,



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reproductive, social, emotional and spiritual consequences of cancer occurrence and needs for medical, psychological and social services for this population. **Purpose:** To analyze the distributions and time trend of cancer and to identify unique cancer patterns among adolescence and young adults in Florida. **Methods:** age-specific cancer incidence and mortality among adults age 15-39 were calculated using Florida Cancer Data System data in 1981-2006. The data were analyzed by sex and race. **Results:** In 2005, there were 3,894 cases young adults, 3.9% of all cancer cases reported in Florida. The major cancers among females were breast cancer, thyroid cancer, melanoma, cervix cancer, and Hodgkin disease. For males, the top five cancers were testes cancer, non-Hodgkin lymphoma, melanoma, Hodgkin disease and cancer of the brain and nervous. The incidence of thyroid cancer among white females was more than two times the rate among black females. The incidence of cancer of the brain and nervous was higher among white males than among black males. On average, more than 600 patients died from cancer in this population every year. Breast cancer and non-Hodgkin lymphoma was the cancer with the highest mortality among females and males, respectively. The overall incidence increased by 21% from 55.1/100,000 in 1981 to 66.9/100,000 in 2006. The overall mortality decreased by 26% from 13.1 /100,000 in 1981 to 9.7/100,000 in 2006. **Conclusions:** The patterns of cancer among adolescence and young adults are quite distinct from that either among children or among older adults. More studies are needed to examine the uniqueness of racial difference in the incidence and mortality in this population.

THE PAPERLESS OFFICE: AUTOMATING QUALITY CONTROL ACTIVITIES IN FLORIDA

M. Alvarez, M Herna, S Manson, G Levin, Florida Cancer Data System (FCDS), University of Miami Miller School of Medicine, Miami, Florida, USA.

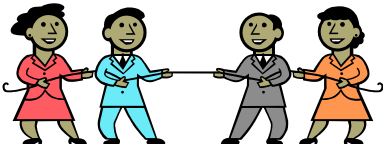
Overview: Quality Control, AHCA and Death Clearance follow back processes are registry processes that require feedback from hospitals on a daily and annual base. The Quality Control process is an ongoing daily activity which requires the exchange of confidential information from the facility and/or contractor to the central registry. AHCA and Death Clearance follow back processes are annual activities that also can include the exchange of confidential information. Florida has taken these once manual processes to full automation through a secure exchange of documents. **Process:** AHCA and Death Clearance Records are matched against the FCDS Database. Facilities are notified through e-mail of the unmatched AHCA and Death Clearance cases. These processes are done to identify any cases that have not been reported to FCDS. Records are then reviewed via the FCDS online IDEA system. The QC Abstract Review Process is automated by selecting one of every 25th record



processed. Each case selected is placed in a QC file ready for visual review. At FCDS, approximately 165,000 incidence abstracts are processed annually. The intent of automating these processes is to not only to eliminate the use of paper but to create a more efficient workflow. The facilities are required to obtain access and must respond to all cases via the web server. Major benefits include; no mailing of patient confidential information, secure transmission of documents, postage cost savings, real-time-no USPS delays and overall time. Creating a paperless environment is not only about "going green", it's also about increasing control and reliability of these processes, benefiting overall data quality.

THE HISPANIC PARADOX AT THE CANCER REGISTRY LEVEL

Pinheiro PS¹, Williams M², Wohler B¹, Easterday S², MacKinnon JA¹, Miller E²; ¹Florida Cancer Data System, Miami FL; ²Texas Cancer Registry, Austin TX

 In 2007, Texas and Florida (2nd and 3rd largest states in number of Hispanics), totaled 12.6 m Hispanics. Studies of cancer survival and prognosis among Hispanics are invariably affected by issues of follow-up. The concept of the Hispanic paradox, where Hispanics have disproportionately better health outcomes than Whites, has been explained by factors including the "salmon theory". This states that the apparent Hispanic "advantage" occurs partly because Hispanics return to their foreign homeland, before death. These death certificates are not obtainable by cancer registries. Inconsistencies in recording Hispanic names and higher proportions of unknown social security numbers may also negatively impact the quality of data linkage between cancer and death records. Both the "salmon theory" and/or data quality issues may bias survival/mortality results in favor of Hispanics, as records for this ethnicity will disproportionately show subjects as alive. In the present joint study between two state cancer registries, we study the availability of death certificates and data quality issues, for non-Hispanic Whites, non-Hispanic Blacks, and for each Hispanic subpopulation. We studied cancers of extremely low survival and for which no significant differences in mortality are expected across ethnic populations and other common cancers, but taking into account stage at diagnosis. For this purpose we use cancer data from the Florida and Texas cancer registries, diagnosed during 1995-2005 to assess the extent to which, out-migration prior to death and data quality issues could contribute to the appearance of a Hispanic mortality advantage and affect the results of population-based survival studies using non-SEER cancer registry data.

Abstracts of Posters presented:

(Continued on page 5)

SPATIAL MODELING OF PANCREATIC CANCER (PC) AND PROXIMITY TO ARSENIC-CONTAMINATED WELL SITES

DJ Lee, JE MacKinnon, R Sherman, LE Fleming, JJ Hu.
Dept of Epidemiology & Public Health, and Florida Center Data System (FCDS), Miller School of Medicine, University of Miami, Miami, FL USA

Introduction: We sought to identify high-risk areas of PC incidence and determine if PC clusters were more likely to be located near arsenic-contaminated drinking water wells. **Methods:** Spatial modeling was applied to PC cases diagnosed between 1998-2002 in Florida (n=11,405). Multi-variable regression was used to determine if sociodemographic indicators, smoking history, and proximity to arsenic-contaminated well sites were associated with PC diagnosis within versus outside a cluster. **Results:** Spatial modeling identified 2581 clusters in which 24.8% of all PC cases were located. Cases living within 4 miles and 1 mile of known arsenic-contaminated wells were significantly more likely to be diagnosed within a cluster relative to cases living more than 4 miles from known sites (ORs= 1.6 [1.4-1.8] and 2.0 [1.6-2.5], respectively). **Conclusions:** Exposure to arsenic-contaminated wells may be associated with an increased risk of PC. Case-control studies are needed in order to confirm the findings of this ecological analysis.



DISPARITIES IN SURVIVAL AMONG WOMEN WITH INVASIVE CERVICAL CANCER: A PROBLEM OF ACCESS TO CARE

KF Brookfield, MC Cheung, J Lucci, LE Fleming, LG Koniaris
Depts of ObGyn, Family Medicine, Surgery, and Epidemiology & Public Health, and Florida Center Data System (FCDS), Miller School of Medicine, University of Miami, Miami, FL USA

Background: To understand the effect of patient race, ethnicity and socioeconomic status (SES) on outcomes for cervical cancer. **Methods:** Using FCDS and Agency for Health Care Administration data (1998-2003), survival outcomes for patients with invasive cervical cancer were compared by race, ethnicity and area-based poverty. **Results:** 5,367 cervical cancers with 43 months overall median survival time. Longer survival for: Whites vs Blacks (47.1 vs 28.8 mnths; $p < 0.001$), insured vs uninsured (63 vs 41.2; $p < 0.001$), affluent communities (53.3 vs 36.9; $p < 0.001$). Improved survival with surgery, but Blacks significantly less likely to have surgical treatment with curative intent compared to Whites ($p < 0.001$). Independent predictors of poorer outcomes were insurance status, tumor stage, tumor grade, and treatment; but race, ethnicity, and SES were NOT independent predictors of poorer outcome. **Conclusions:** Race, ethnic and SES disparities in cervical cancer survival were explained by late-stage presentation and under-treatment. Earlier diagnosis and greater access to surgery and other treatments.



New Floridian CTRs from the spring exam:

**Barbara S. Anderson
Gerardo J. Gallardo
Brent J. King
Laguita M. Malone
Jorge L. Migoya Fragas
Mary-Kay Ramos**

FCDS Makes Headlines

by Recinda Sherman, MPH, CTR



Our very own Dr. Paulo Pinheiro recently published a landmark study in the journal *Cancer Epidemiology, Biomarkers and Prevention* -- Cancer Incidence in First Generation U.S. Hispanics: Cubans, Mexicans, Puerto Ricans, and New Latinos 2009;18(8). The co-authors, most of whom are affiliated with FCDS, include Recinda Sherman and Drs. Ed Trapido, Lora Fleming, Youjie Huang, Orlando Gomez-Marin, and David Lee.

Dr. Pinheiro's paper published, for the first time, age-adjusted cancer rates for Hispanic subgroups—Cubans, Mexicans, Puerto Ricans, and, the aggregate group, New Latinos in Florida. These rates hinged on work he did for FCDS on improving the quality and completeness of the Hispanic Origin variable in the registry data as well as working with the US Census to generate appropriate denominator estimates. At FCDS he developed an Hispanic Origin Identification Algorithm, HOIA—an improvement over the NAACCR NHIA instrument particularly for states with diverse Hispanic populations, such as Florida. Specifically, HOIA was designed to improve the specificity of the Hispanic subgroup information.^a

The paper evaluated the types of cancers occurring in each Hispanic subpopulation (for which there was reliable census denominator data) and compared cancer rates among the subgroups here in Florida with rates in their homelands. The results confirm that different Hispanic subgroups have different cancer rates. “Hispanics are not all the same with regard to their cancer experience”, says Dr. Pinheiro, “Targeted interventions for cancer prevention and control should take into account the specificity of each Hispanic subgroup.”

More provocatively, the study also indicates that for some cancers, such as colorectal cancer, the rates are higher in the population groups here in the US than in their homelands. This suggests that once they immigrate to the US, “changes in their environment and their lifestyles make them more prone to develop cancer”, says Dr. Pinheiro. These results present important opportunities for further study to assess which modifiable environmental and lifestyle factors are important in the development of cancer.

This study received wide media coverage on the local, national, and international level including the New York Times, CNN, ABC, NPR, BBC, the AP and many others. Dr. Pinheiro described his study to both English and Spanish language outlets. It was a tremendous experience to see the registry data, the result of all our efforts, promulgated by the media in such a high profile fashion. Dr. Pinheiro also won a research award from the University of Miami for this work.

a. For information specific to the algorithm please see:

- 1) Pinheiro PS, Sherman R, Fleming L, Gomez-Marin O, Wohler B, MacKinnon J, Levin, G. (2008) HOIA: An Alternative Hispanic Origin Identification Algorithm for Cancer Registries. *JRM* 2008;35(4) 149-155
- 2) Pinheiro PS, Sherman R. Why an Alternative Algorithm for Hispanic Subgroup May Be Useful. Letter to the Editor. *JRM* 2009; 36(1):3-4
- 3) Pinheiro PS, Hispanic Ethnicity and Birthplace *The Register* 2008(April);39 1-2.

CALENDAR OF EVENTS

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NAACCR CANCER REGISTRY & SURVEILLANCE WEBINAR SERIES 2009

- Time:** 9:00 am—12:00 pm
- Locations:** Boca Raton Community Hospital (Boca Raton, FL)
Gulf Coast Medical Center (Panama City, FL) *starting October 2009*
H. Lee Moffitt Cancer Center (Tampa, FL)
Shands University of Florida (Gainesville, FL)
- Contact:** Meg Herna at 305-243-2625 or mherna@med.miami.edu
- To Register:** <http://fcds.med.miami.edu>
- Information:** <http://www.naaccr.org/filesystem/pdf/2008-2009%20webinar%20schedule.pdf>
- Dates:**
- September 3, 2009 ✧ “Assessing and Using Cancer Data”
 - October 1, 2009 ✧ 2010 Cancer Data Collection Updates: Standards Volume II, Version 12
 - November 5, 2009 ✧ Collection Cancer Data: Colon/Rectum/Appendix

PRINCIPLES AND PRACTICE OF CANCER REGISTRATION, SURVEILLANCE AND CONTROL—BASIC TRAINING

- Date:** October 12-16, 2009
- Location:** Emory University—Atlanta, GA
- Website:** <http://www.sph.emory.edu/GCCS/training/practice/index.php>

PRINCIPLES OF ONCOLOGY FOR CANCER REGISTRY PROFESSIONALS

- Date:** November 16-20, 2009
- Location:** Reno, NV
- Website:** <http://www.afritz.org>



We're Gold Again!

This year is the 12th anniversary of the NAACCR certification process. This award recognizes the population-based cancer registries that have achieved excellence in the areas of completeness of case ascertainment, quality of the data and timeliness.





FCDS has won “Gold” status certification for the past 6 years. Thanks to all who have contributed in helping us achieve this excellence award.

COMPLETENESS REPORT—2008 CASE REPORTING

Month	Complete	Expected
July 2008	1%	8%
August 2008	3%	17%
September 2008	12%	25%
October 2008	20%	33%
November 2008	27%	41%
December 2008	32%	50%
January 2009	45%	58%
February 2009	53%	66%
March 2009	64%	75%
April 2009	71%	83%
May 2009	79%	91%
June 2009	98%	100%

COMPLETENESS REPORT—2009 CASE REPORTING

Month	Complete	Expected
July 2009	4%	8%
August 2009	8%	17%

Register

A joint project of the Sylvester Comprehensive Cancer Ctr
and the Florida Department of Health

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The FCRA/FCDS Task Force is actively working on many issues that all registrars are facing. If you have any questions, issues or suggestions that you would like the task force to review, please email them to taskforce@fcra.org.

The task force meets the first Thursday of every month. We will respond back to your inquiries as quickly as possible.



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