



Florida Statewide Cancer Registry



Florida Cancer Data System



FCDS Update: The State of the State 2025 The April Edition

Gary M. Levin, BA, ODS
FCDS Virtual Annual Meeting
4/30/2025



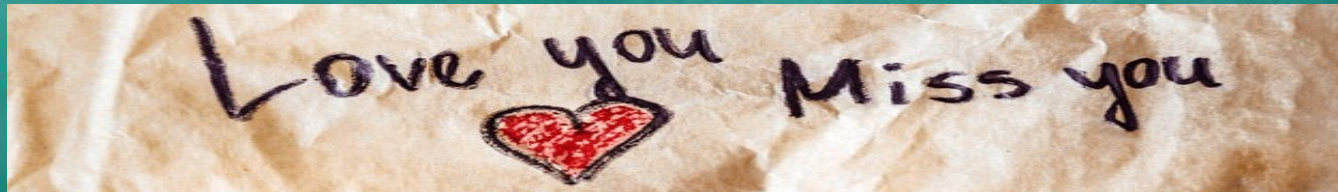
Welcome to the 2025 FCDS Virtual Annual Meeting

- New Certified Tumor Registrars
- Florida Department of Health
- CDC/NPCR
- FCDS Staff
- First Time Attendees - Feel Free to Ask Questions



Betty Fernandez

Retired After 43 Years of Service



Welcome New FCDS Staff

- **Data Acquisition/Quality Control/Education**
 - Barbara DeArmon-Neyland, BS, ODS - Quality Control Coordinator
 - Dawn Mason, BS, ODS - Senior Field Coordinator
 - Mahima Jain, MBA - Senior Field Coordinator
 - Rhonda L. Buchenhain, BS, RHIA, ODS - Senior Field Coordinator
- **Statistical**
 - Hunter Stiff, MPH - Senior Research Associate 3
 - Spencer Hays, PhD - Senior Research Associate 3
- **Administrative**
 - Frances Castellvi Senti - Business Manager
 - Katherine Lundgren - Accountant



Special Thanks

Meg Herna

All Our Volunteer Presenters

Mark Rudolph - Managing Zoom Sessions

Katherine and Danielle for Organizing

All Attendees for Participating



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Florida Statewide Cancer Registry




Florida Cancer Data System



History/Background



History/Background

- Legislatively Mandated
 - Statewide, Population Based -1981
 - Second Largest in Central Cancer Registry in the Nation
 - UMMSM operates under Department of Health Contract
 - CDC - NPCR Enhancement 1995
 - Incidence Only
- 

History/Background

- Data Collection Sources
 - 1981-Present
 - Hospitals
 - 1995-Present (CDC/NPCR)
 - Ambulatory Surgical
 - Radiation Therapy
 - Pathology Labs
 - Death Certificates
 - Physician Offices
 - Medical Claims



Reporters

Florida Reporting Sources in 2024

Reporting Source	# of Registered Facilities
Hospitals	239
Radiation Treatment Centers	93
Ambulatory Surgery Centers	523
Pathology Labs (CLIA's)	438
Hematology/Oncology	582
Hematologists	31
Oncologists	210
Urologists	497
Dermatologists	1375
Other Specialty Physicians	2826
Total	6,814

The FCDS Database

- 7,650,113 (~310,000/Year) - Abstracts
- 4,373,755 - Patients
- 5,502,782 - Tumors
- 145,000 - New Incidence/Year
- 14,192,392 (~443,000/Year) - Hospital/Surgery Centers Discharges
- 1,402,261 (~77,000/Year) - Radiation Treatment Centers
- 19,200,252 (~546,000/Year) - Pathology Reports



The FCDS Database


- 7,105,877 (~251,000/Year) - Death Certificates from Vital Statistics
- 97,341,663 (~14,380,000/Year) - Physician Medical Claims
- 129,500 Recurrence/Treatment Enhancement Abstracts
 - Source: Four NCI Cancer Centers
 - Recurrence Information Collected
 - 42.22% - Disease-Free
 - 32.19% - Shows Recurrence
 - 20.11% - Never Disease Free
 - 3.42% - Recurrence But Type Unknown
 - 2.06% - Unknown If Recurrence or Disease-Free



External Data Source Linkages

- AHCA - Discharge Data (Hospital and Surgery Centers)
 - Florida Vital Statistics - Death Certificates
 - National Death Index
 - Indian Health Services
 - Department of Motor Vehicles
 - Voters Registration
 - Residence Histories - Lexis/Nexis
 - Future - Medicaid and Health Information Exchange (HIE)???
- 

Data Dissemination

- Tableau Dashboards
 - Cancer Data Query
 - Researchers Data Requests (DREAMS Automated Data Request)
 - Stat File
 - Tabular Data
 - Ad Hoc (Require DOH IRB Approval)
 - Patient Contact Studies (Require DOH IRB Approval)
 - Linkages (Require DOH IRB Approval)
 - Out of State Data Exchange
 - Florida CHARTS
- 

Data Dissemination

- Florida Breast and Cervical Early Detection Program
- Florida Colorectal Cancer Control
- Florida Environmental Health Public Tracking
- DOH Cancer Concerns
- National Call for Data Submissions (NAACCR, NPCR, NCCR, VPR)
- Annual Report to the Nation on the Status of Cancer

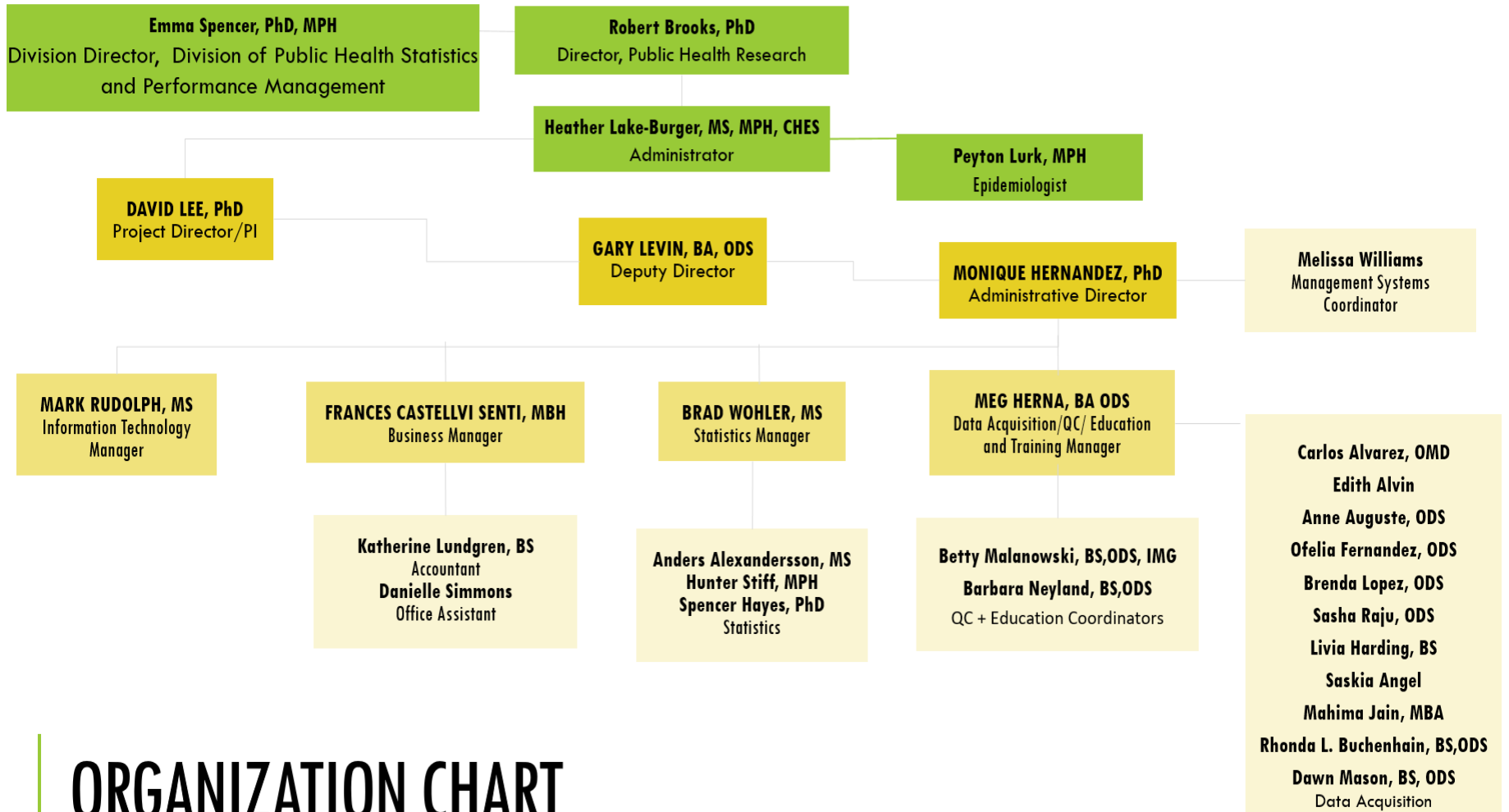


Data Dissemination

- **Contribute Data to the Florida Cancer Plan 2020-2025**
- **Contribute Data to The State of Cancer in Florida Annual Report**
- **Leadership Role in Florida Cancer Plan Goal 2 - Data**
 - **Cancer Biology Workgroup**
 - **Social Determinants of Health Workgroup**
 - **Screening Data Collection Workgroup**
 - **Data Access and Utilization Workgroup**



FCDS Organizational Chart



ORGANIZATION CHART

FCDS

Florida Statewide Cancer Registry



Florida Cancer Data System



Certification

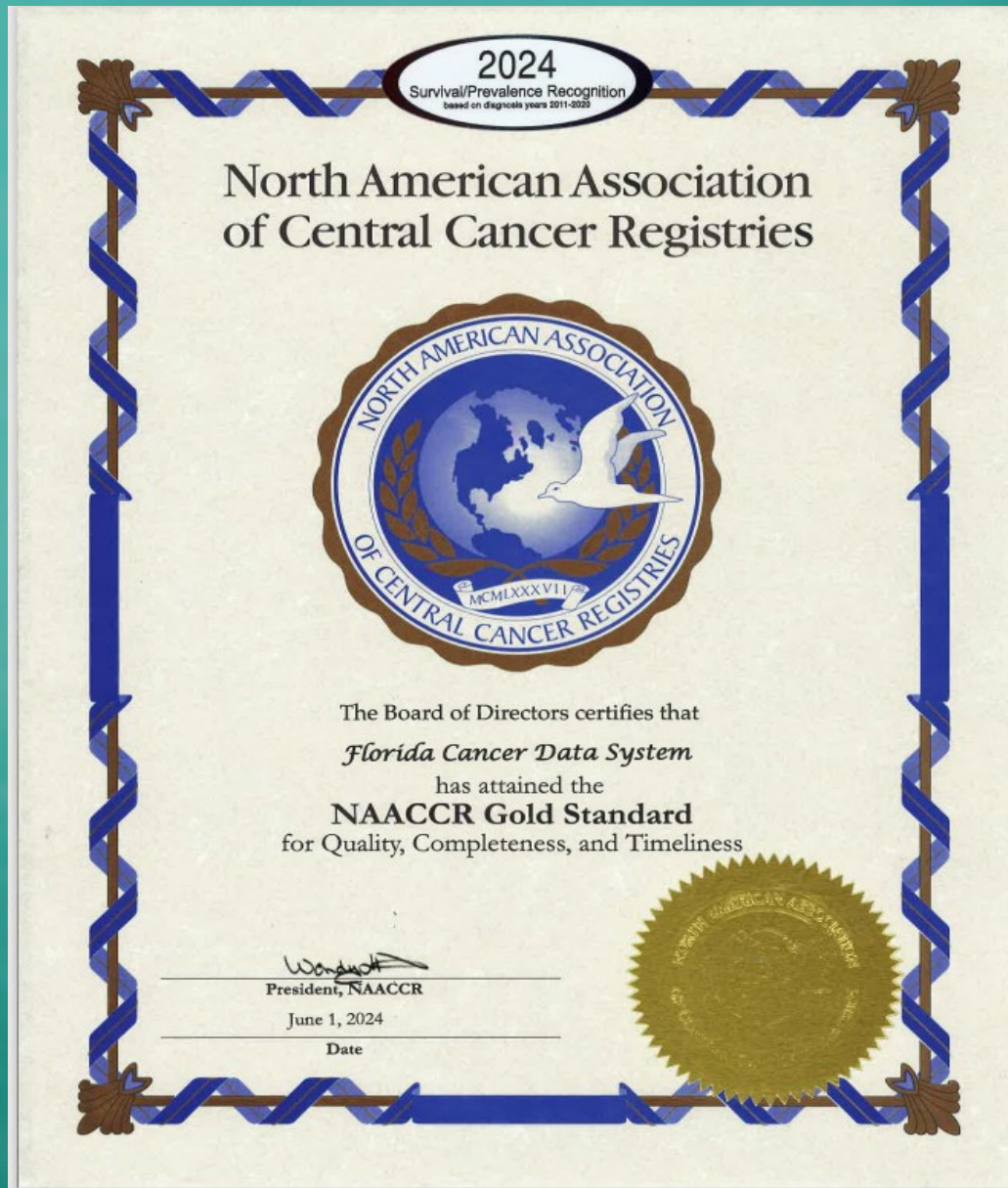


National Certification

- Certification Criteria
 - 95% Complete
 - $\leq 2\%$ Unknown Age at Diagnosis, Gender, State/County
 - $\leq 3\%$ Unknown Race
 - $\leq 3\%$ Death Certificate Only Cases
 - $\leq 1/1000$ - Duplicate Primary Cases
 - 100% Passing Edits
 - Data Submitted Within 23 Months of Year Closed
 - Included in Cancer In North America (CiNA) Dataset
 - Inclusion in United States Cancer Statistics (USCS)



NAACCR Gold Certification



2023 NPCR Registry of Distinction

NATIONAL PROGRAM OF CANCER REGISTRIES
2023 REGISTRY OF DISTINCTION

FLORIDA CANCER DATA SYSTEM



In recognition of providing complete and timely
National Program of Cancer Registries data in 2023.

Vicki Benard, Ph.D.
Chief, Cancer Surveillance Branch
Division of Cancer Prevention and Control



U.S. Cancer Statistics Registry for Surveillance

NATIONAL PROGRAM OF CANCER REGISTRIES
U.S. CANCER STATISTICS REGISTRY FOR SURVEILLANCE

FLORIDA CANCER DATA SYSTEM



Provides critical and high-quality data that are included in the U.S. Cancer Statistics, the official federal cancer statistics.

Vicki Benard, Ph.D.
Chief, Cancer Surveillance Branch
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FCDS Updates



FCDS Updates: Diagnosis Year 2025

•New Data Items

- PTLD-Post Transplant Lymphoproliferative Disorder (Item 1172)
 - Lymphoma (00790)
 - Lymphoma-CLL/SLL (00795)
 - Plasma Cell Disorders (00822)
 - Plasma Cell Myeloma (00821)
 - Primary Cutaneous Lymphoma (00812)
- PD-L1 (Item 1174)
 - Lung V9 (09360)

•Name Changes/Updated Coding Instructions



FCDS Updates: Diagnosis Year 2025

- Cancer PathCHART Updates for 2025
- No Updates to Surgery Codes
- Retired Data Items
- Updates to the Multiple Primary Rules
 - Subtype Histology Codes added to NOS
 - New Terminology



FCDS Project Highlights

- National Childhood Cancer Registry
- NACCR Virtual Pooled Registry
 - 14 Phase 1 Linkages
- CDC Lexis/Nexis Pilot
- DOE/NCI NLP Pilot
- CDC Data Quality Evaluation
- CDC/NPCR Audit



FCDS Project Highlights

- Modification Abstracts
 - Collect Recurrence Information
 - 4 NCI Cancer Centers Participating
 - No Funding
- CCRAB Florida Cancer Plan - Objective 2
 - 2.2 Cancer Biology Pilot
 - Work Plan Completed
 - No Funding
 - 2.3 Social Determinants of Health Pilot
 - In the process of linking to the FCDS Database
 - Plans to incorporate in the FCDS Data Request System
 - No Funding



FCDS Project Highlights

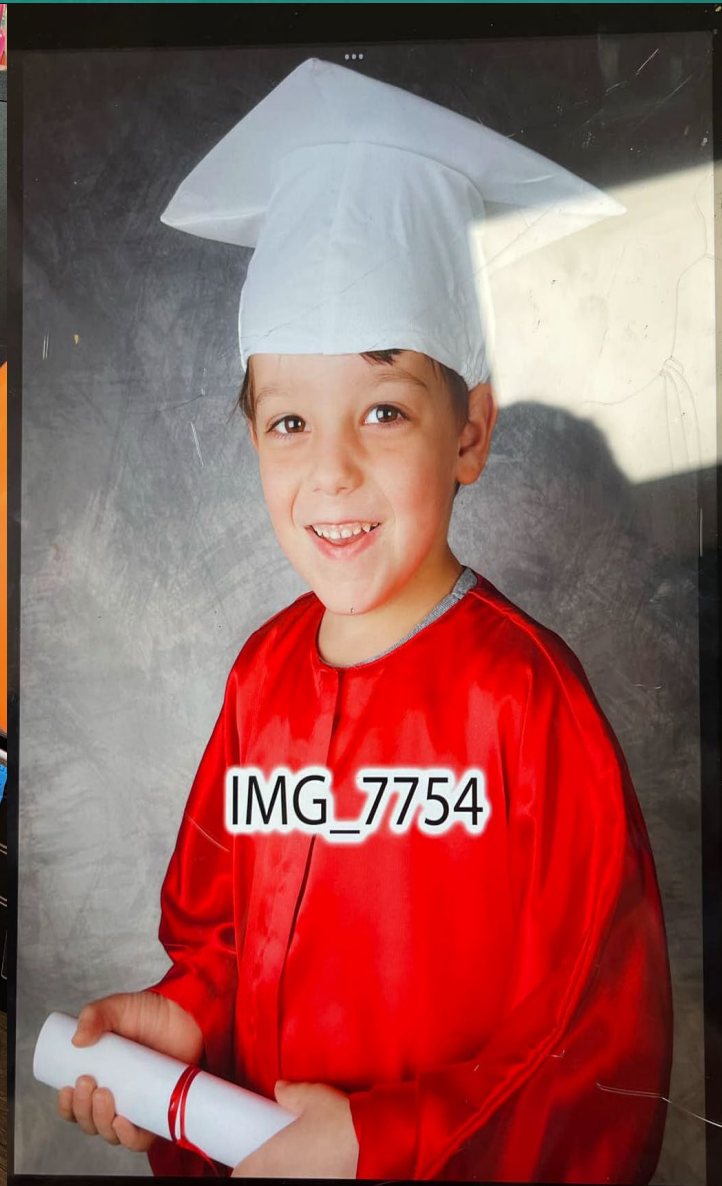
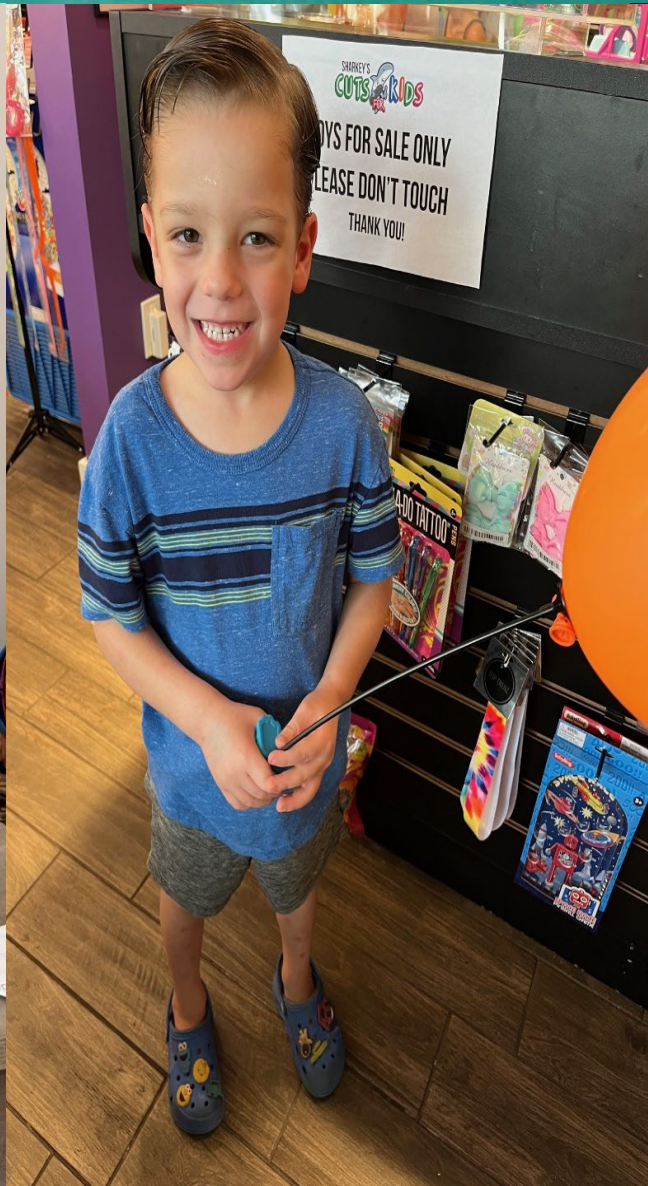
- CCRAB Florida Cancer Plan - Objective 2
 - 2.4 Lung Cancer Screening Registry Pilot
 - Funding Received
 - Developing DUA for two volunteer reporters
 - Model from ACR Lung Cancer Screening Registry (LCSR)
 - 2.5 Increase Data Access and Utilization
 - ODS Researcher Assistance Program
 - No Funding



Our Grandson Caleb Last Meeting



Our Grandson Caleb Almost 5 Years Old



New Granddaughter Elizabeth (Ellie) Ann - Born 11/20/2024



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Thank You

Stay Smart, Safe and Healthy Have a Great Meeting



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MILLER SCHOOL
of MEDICINE



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UHealth
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Thank You
Questions?

