

# Cancer Clusters and Related Activities at CDC

**Beverly S. Kingsley PhD, MPH**  
**National Center for Environmental Health**  
**Environmental Hazards and Health Effects**  
**Health Studies Branch**



# Cancer Clusters

- **Role of CDC/NCEH**
- **Environmental Agents and Cancer**
- **Cluster Science**
- **Cancer Cluster Activities at CDC**
- **State Protocols**
- **Next Steps**

# CDC and Cancer Clusters

## **1960's-1980's:**

Multiple cancer cluster investigations

Cause-Effect relationships not shown

Move towards uniform methods by health depts

**1989** : National Conference on Clusters of Health Events AJE July 1990; 132(1)

**1990** : MMWR Guidelines for Investigating Clusters of Health Events, 1990;39:1-16

## **1990-present:**

Participation in a few cluster investigation

# **NCEH Involvement in Cancer Clusters**

- **Centralized office to handle clusters**
- **Prior to 2002 CDC cluster response by NCEH, NCCDPHP, NIOSH, ATSDR**
- **2002 need for lead office recognized**
- **NCEH/EHHE assigned lead in cancer clusters**

# Classic Cluster Studies

## Occupational

- 1770's Chimney sweeps - scrotal cancer
- 1920's Radium dial painters – osteosarcoma
- 1960's asbestos workers - mesothelioma
- 1970's vinyl chloride monomer – angiosarcoma

## Non occupational:

- 1971 diethylstilbestrol -vaginal carcinoma

# Environmental Exposures and Cancer

## Known

- Benzene - leukemia
- Arsenic – skin, liver cancer
- Radon - lung cancer
- Aflatoxin – liver
- Epstein Barr Virus – nasopharyngeal, Burkitt's lymphoma
- 2,3,7,8 TCDD- sarcoma, hematopoietic

## Suspected

- Trichloroethylene - various cancers
- Disinfection By Product's - bladder cancer

# Recent Cluster Investigations

## Long Island NY

[www.health.state.ny.us/nysdoh/consumer/cancer/cancerqasave.htm](http://www.health.state.ny.us/nysdoh/consumer/cancer/cancerqasave.htm)

## Woburn MA

[www.state.ma.us/dph/behav/cau/reports/woburn/woburn.htm](http://www.state.ma.us/dph/behav/cau/reports/woburn/woburn.htm)

## Toms River NJ

[www.state.nj.us/health/eoh/hhazweb/dovertwop.htm](http://www.state.nj.us/health/eoh/hhazweb/dovertwop.htm)

## Fallon NV

[www.cdc.gov/nceh/clusters](http://www.cdc.gov/nceh/clusters)

# Issues in Cluster Investigation

- **Exposure Assessment**
- **Denominators**
- **Delineating boundaries( census tracts, zip codes, circular boundaries)**
- **Migration**
- **Latency**
- **Records/data sources/case ascertainment**
- **Complex disease/ risk factors**

# **The Status of Cancer Cluster Activities at CDC**

# **NCEH initiated seven projects on cancer clusters**

- 1. Uniform CDC inquiry system: CCPITS**
- 2. Cluster Web site**
- 3. Review of state protocols on clusters**
- 4. Reviewed media coverage of cancer clusters**
- 5. Site visits to states w/cluster investigations**
- 6. Convened two workshops**
- 7. Created electronic cancer cluster listserv**

# **Cancer Cluster Public Inquiry Triage Inquiry System**

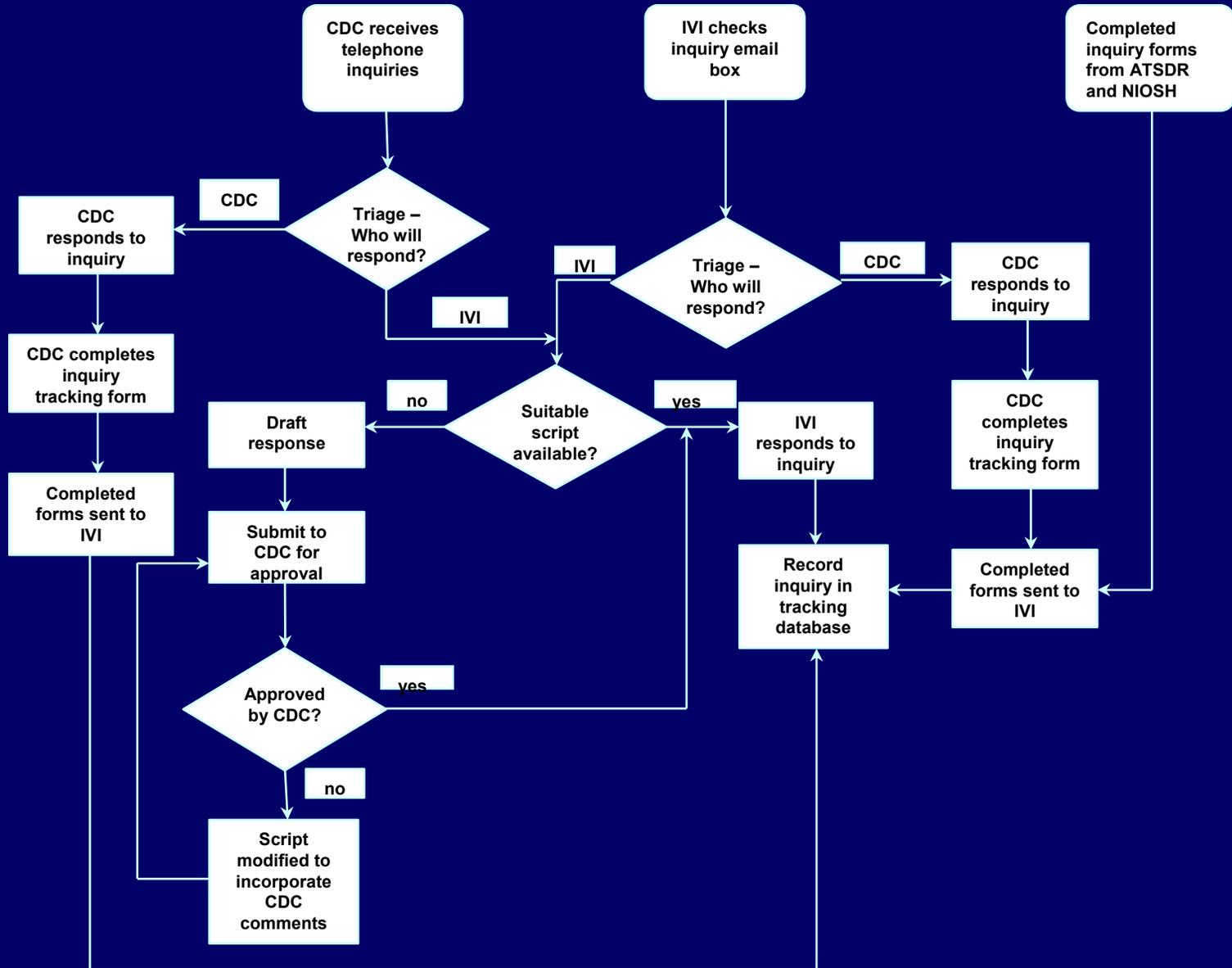
**May 2002: NCEH initiated CCPITS**

## **Goals:**

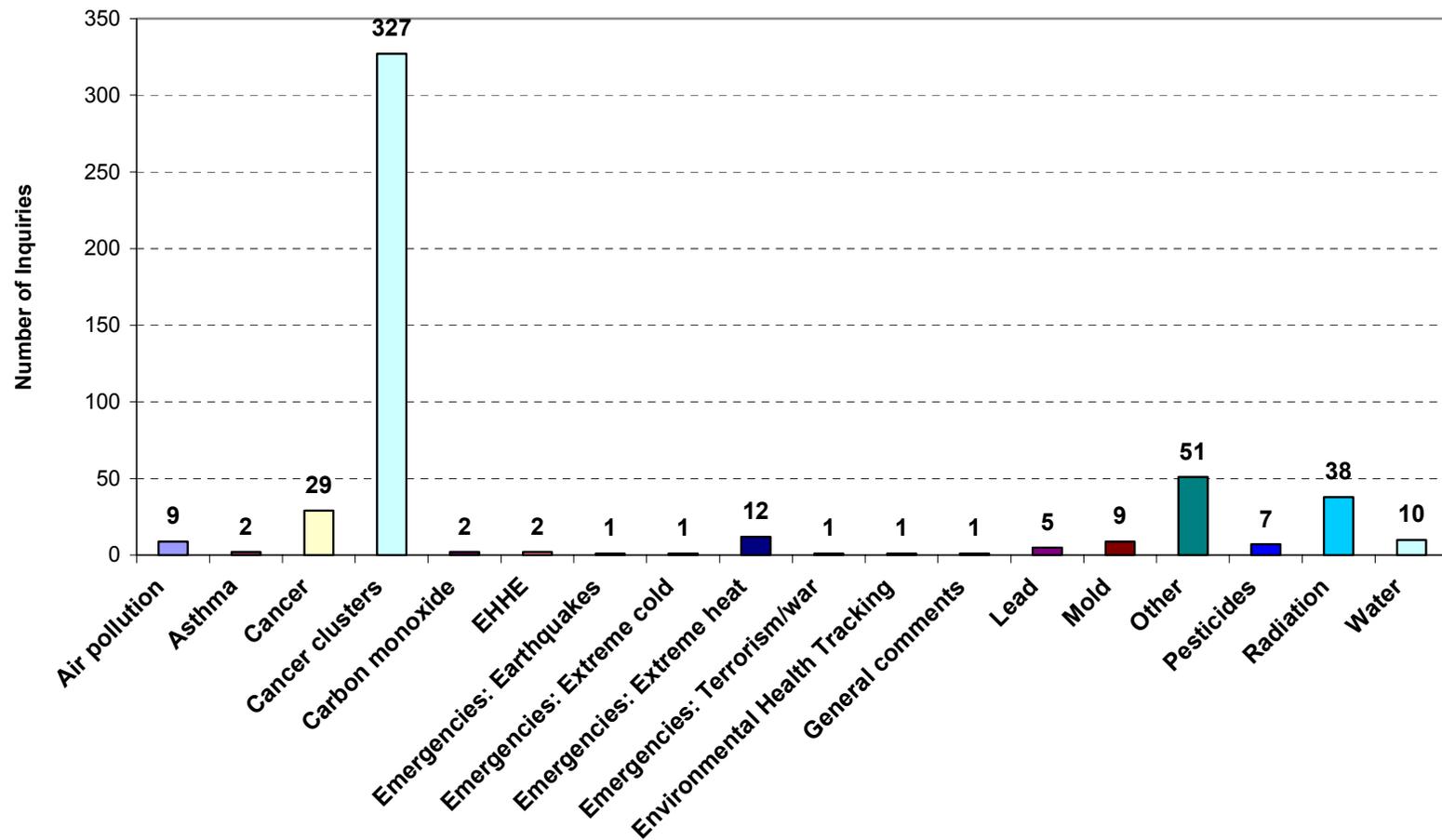
**To provide centralized system for accurate, consistent, and timely response to cluster inquiries**

**To increase coordination/info sharing within CDC and among partners: NCCDPHP/DCPC, NIOSH, ATSDR, state health departments**

# CCPITS Inquiry Process Flowchart



# Number of Inquiries by Subject -- May 2002 -September 2003\*



\*An individual inquiry may have more than one subject entered. Only air pollution inquiries pertaining to additional subjects are included here

# **CCPITS Contact Information**

**Address:**

**Division of Environmental Hazards and Health  
Effects**

**National Center for Environmental Health  
Centers for Disease Control and Prevention**

**Re: Cancer Clusters**

**1600 Clifton Rd, NE, MS E-19**

**Atlanta, GA 30333**

**Toll Free: 1-888-232-6789**

**E-mail: [EHHEinq@cdc.gov](mailto:EHHEinq@cdc.gov)**

**Web site: <http://www.cdc.gov/nceh/clusters>**

# Web Resources

[www.cdc.gov/nceh/clusters](http://www.cdc.gov/nceh/clusters)

- **Cancer Clusters**
- **General Information**
  - About cancer clusters
  - Cancer cluster FAQ
- **CDC activities**
  - Investigations
- **Resources**
- **Contacts for more information**

# State Protocol Review

In collaboration with RTI International -

- Requested copies of any documentation related to cancer cluster inquiry and investigation protocol
  - 50 states and territories responded
  - 6 states did not respond
- Developed a tool to compare the protocols
  - more than 300 descriptors
  - At least 2 independent raters

# State Protocol Review

Comparison parameters included-

- Level of detail
- Education provided to callers
- Responsibility for investigation/gathering information
- Decision tree/algorithm
- Sequence of activities
- Available data resources/delineate responsibilities

# State Protocol Review

- **Level of detail varied significantly among states**
- **Length of protocol did not predict level of detail**
- **Many followed 1990 guidelines**
- **Every state provided education to callers**
- **Caller often required to provide info about cancer type(s), number and location of case(s), potential exposures**

# **State Protocol Review** (cont'd)

- **Most states have decision tree/algorithm to proceed toward investigation**
- **Great variation among states**
- **Variety and depth often reflect resources**
- **Most states not specific about roles and responsibilities**
- **Majority of states' protocols did not include communications or community liaison plans**

# State Protocol Review

**Review Instrument -**

**There is no gold standard for cancer cluster protocols.**

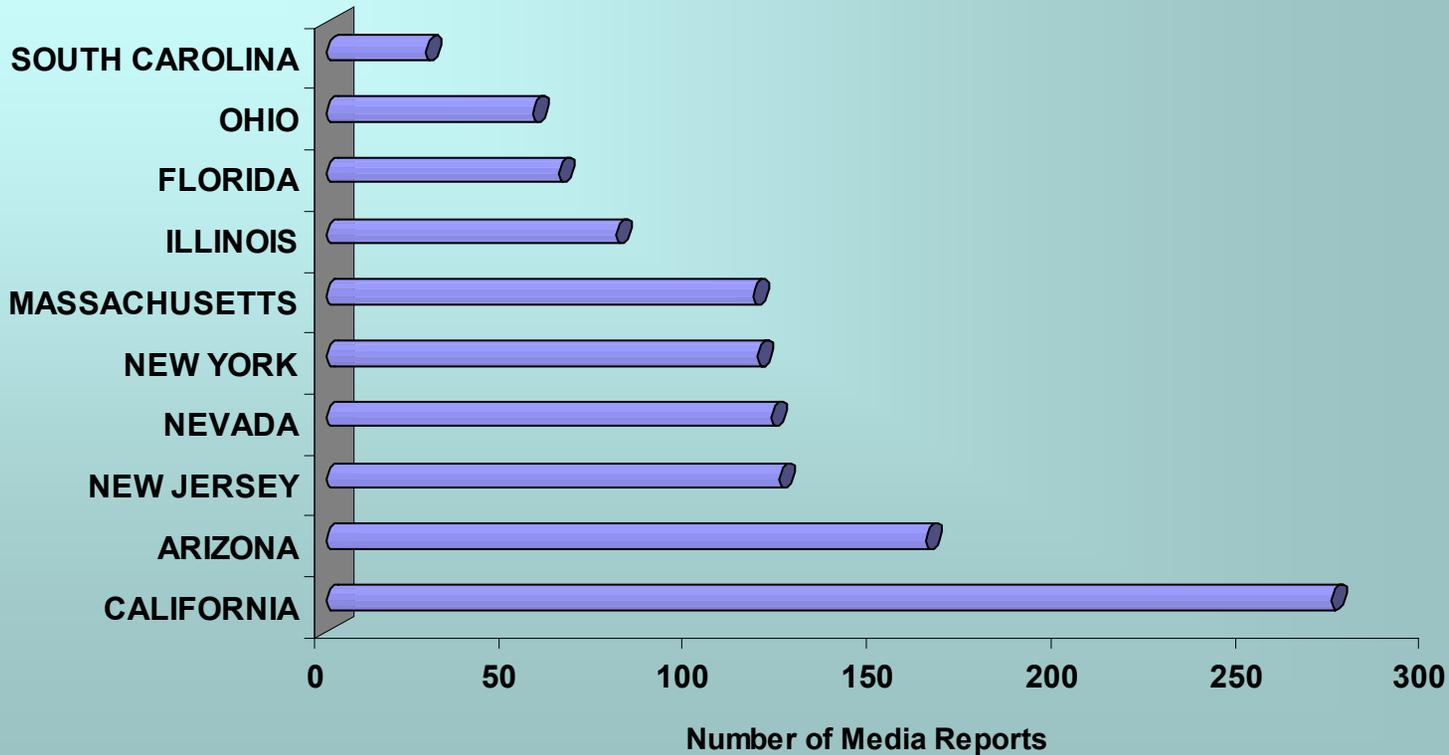
**The 1990 Guidelines were the only uniform baseline available.**

# **Media coverage of cancer cluster reports**

- **Identify and characterize media reports on cancer clusters via extensive literature search**
- **Between 1977-2001 there were 1440 reports**

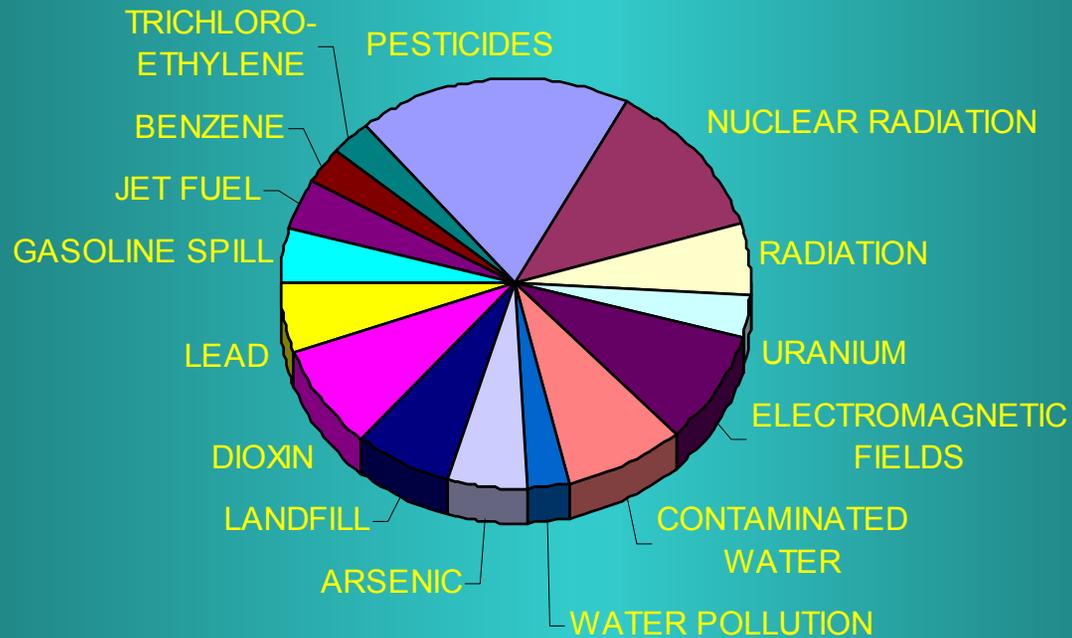
# Media coverage

The Top 10 States Cited in Media Reports,  
1977 - 2001



# Media coverage

## Top 15 Environmental Exposures Reported in Newspapers



# State site visits 2002

**Goal: To further understand state health departments' experiences during recent high profile cancer cluster investigations**

- **New Jersey.** Childhood leukemia, brain, and CNS cancers in Toms River Township
- **Arizona.** Case-referent study of childhood leukemia in Maricopa County, 1965-1990
- **Ohio.** Incidence of leukemia in Marion County.

# State site visits

## Commonalities across sites

- **Protocols continue to evolve**
- **Educational component pivotally important**
- **Standardized forms enhance information gathering**
- **Tracking database increases effectiveness**
- **Decision trees are state-dependent**
- **Established procedure important**
- **Capable, trained staff essential**
- **Reliability of data sources predicts success**

# Workshops

**Two one-day workshops March 11 and 12, 2003**

## **Goals:**

- Dialogue**
- Assess capacity at the state level and develop mechanisms for state-federal communication and collaboration**

## **Participants**

California

Missouri

Washington

Georgia

Minnesota

Texas

Florida

New York

Massachusetts

So. Carolina

# Workshops

## Lessons learned during the workshops: Strengths

- All states take a systematic approach
- All states triage incoming inquiries
- Response varies greatly depending upon state experience and politics
- All states interested in better science and methods
- All states provide education to caller
- Most states generally follow 1990 CDC guidelines
- All states have web sites that address cancer clusters

# Workshops

## Lessons learned during the workshops: Limitations

- **Scientific methods inadequate**
- **Insufficient staff dedicated to topic**
- **Data quality unpredictable**
- **Appropriate control or reference populations problematic**
- **Inherent complexities: small numbers, latency**
- **Public trust/distrust**
- **Media influence**
- **Politics vs. science**

# Workshops

## Lessons learned during the workshops: States' wants and needs

- **Validation of state response**
- **Funding, additional FTEs**
- **Training (CDC sponsored workshops about methods, media)**
- **Information/data sharing (CDC-sponsored listserv)**
- **Assistance with complex investigations**
- **Enhanced credibility with the public**
- **Centralized CDC contact**
- **Validated educational materials**

# Cancer Cluster Listserv

- **NCEH/CDC sponsored**
- **Mechanism for communication, information dissemination**
- **- More than 150 participants**
  - State health departments**
  - Cancer registries**
  - Academics**
  - Federal government**

# Lessons Learned

- **Cancer clusters continue to concern the public**
- **Strong similarity among state response plans**
- **Need for state and federal coordination**
- **Time to consider new approaches**
  - **genetic component of cancer clusters**
  - **aggregating data across states**
  - **uniform questionnaire modules**

# Next Steps in Cancer Cluster Activity for NCEH

- Continue CCPITS Inquiry System
- Future CDC-sponsored workshops/training
- Enrich NCEH / clusters website
- Continue providing assistance to states
- Increase publication activity on cancer clusters

