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-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

Woburn MA
www.state.ma.us/dph/behcau/reports/woburn/woburn.htm

Toms River NJ
www.state.nj.us/health/eoh/hhazweb/dovertwp.htm

Fallon NV
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

CDC receives telephone inquiries

Triage – Who will respond?

CDC responds to inquiry

CDC completes inquiry tracking form

Draft response

Suitable script available?

yes

no

Approved by CDC?

yes

no

Script modified to incorporate CDC comments

CDC completes inquiry tracking form

Completed forms sent to IVI

IVI checks inquiry email box

Triage – Who will respond?

IVI responds to inquiry

Record inquiry in tracking database

CDC responds to inquiry

CDC receives telephone inquiries

Triage – Who will respond?

IVI

Completed inquiry forms from ATSDR and NIOSH

CDC

IVI

IVI responds to inquiry

Record inquiry in tracking database

Completed forms sent to IVI
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
Web site: http://www.cdc.gov/nceh/clusters
Web Resources

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

- CALIFORNIA
- ARIZONA
- NEW JERSEY
- NEVADA
- NEW YORK
- MASSACHUSETTS
- ILLINOIS
- FLORIDA
- OHIO
- SOUTH CAROLINA

Number of Media Reports
Media coverage

Top 15 Environmental Exposures Reported in Newspapers

- Pesticides
- Nuclear Radiation
- Radiation
- Uranium
- Electromagnetic Fields
- Contaminated Water
- Water Pollution
- Arsenic
- Lead
- Dioxin
- Landfill
- Gasoline Spill
- Jet Fuel
- Benzene
- Trichloroethylene

PESTICIDES
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
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
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
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