Summary of the Rhabdomyosarcoma (RMS) and Pleuropulmonary Blastoma (PPB) Cancer Cluster Investigation

NH Department of Health & Human Services
Division of Public Health Services
May 11, 2017

NH DIVISION OF
Public Health Services
Improving health, preventing disease, reducing costs *for all*
New Hampshire Department of Health & Human Services

Surveillance Report Update

Standardized Incidence Ratio (SIR)

- The standardized incidence ratio (SIR) is a measure that compares the cancer rate in one area with a comparison population, taking into account differences in age in the different communities
- An SIR of 1 is the same as expected (normal). An SIR greater than 1 suggests more cancer, and an SIR less than 1 suggests less cancer
- Not all differences in cancer numbers (i.e. SIRs) are statistically significant. The Confidence Interval (CI) is used to assess significant differences – if the CI includes the value of 1.0, the SIR does not indicate a significant difference

Standardized Incidence Ratio (SIR)

- If we expect 10 cases and find 10 cases:
  SIR = 10/10 =1.0
- If we expect 10 cases and find 5 cases:
  SIR = 5/10 = 0.5
- If we expect 10 cases and find 20 cases:
  SIR =20/10 = 2.0

Updated Cancer Numbers, 2005-2015
(5-town Area of Rye and Surrounding 4 Towns)

- Over 11 years (2005-2015), there were a total of 19 children with any malignant cancer
- Numbers of all pediatric cancers were not higher than expected
- Numbers of Leukemia and Non-Hodgkin's Lymphoma were not higher than expected
- No new cases of pediatric RMS or PPB (the SIRs remain elevated)

Updated Cancer Numbers, 2005-2015
(5-town Area of Rye and Surrounding 4 Towns)

- There were a total of 7 “brain and other CNS” cancers reported, which was higher than expected, but this was a diverse group comprised of 4 different types of cancer
- Does not meet the definition of a cancer cluster
- There have been reports about brain cancer that we continue to evaluate based on our investigation protocol evaluating number, specific type of cancer, and location of reported concern

Background Information on Cancer Cluster Investigations

Cancer Is Common

- Cancer is the leading cause of death in NH
- Cancer is the 2nd leading cause of death in U.S.
- Cancer is the 2nd leading cause of death in U.S. in children aged 5-14 years (second only to unintentional injury)
- 1 out of 4 deaths in NH and nationally are due to cancer

“Cancer” Is Not a Single Disease

- Cancer is a term used for diseases where abnormal cells in our body divide without control, spread and grow to invade other tissues
- Cancer is not a single disease, but comprised of many different types: more than 100 kinds of cancer
- Cancers are named for the types of cells/tissue from which they arise

Different Cancers Have Different Causes

- Genetics
- Lifestyle factors: Diet and exercise (alcohol, red meat)
- Behaviors (tobacco use)
- Infections (HPV virus, hepatitis B & C)
- Environmental exposure (UV light, radon gas, arsenic, asbestos)
- Chemicals (benzene, formaldehyde)
- Radiation (medical radiation)
- Sporadic, no identified causes

What is a Cancer Cluster?

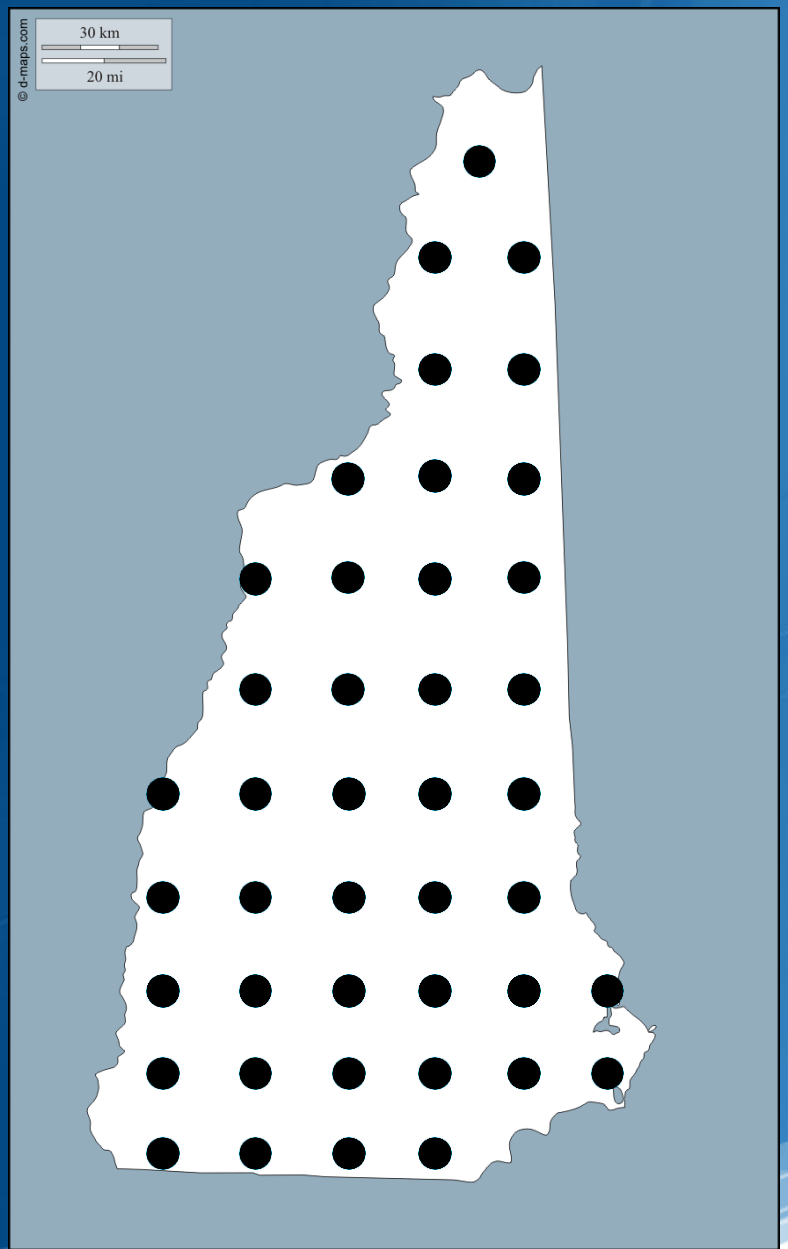
- Greater # of cancer cases than expected,
- of the same type of cancer, or types known to have the same cause,
- occurring within a defined group of the population (e.g. demographics),
- in a specific geographic area,
- over a defined period of time.

NH DIVISION OF
Public Health Services
Improving health, preventing disease, reducing costs for all
New Hampshire Department of Health & Human Services

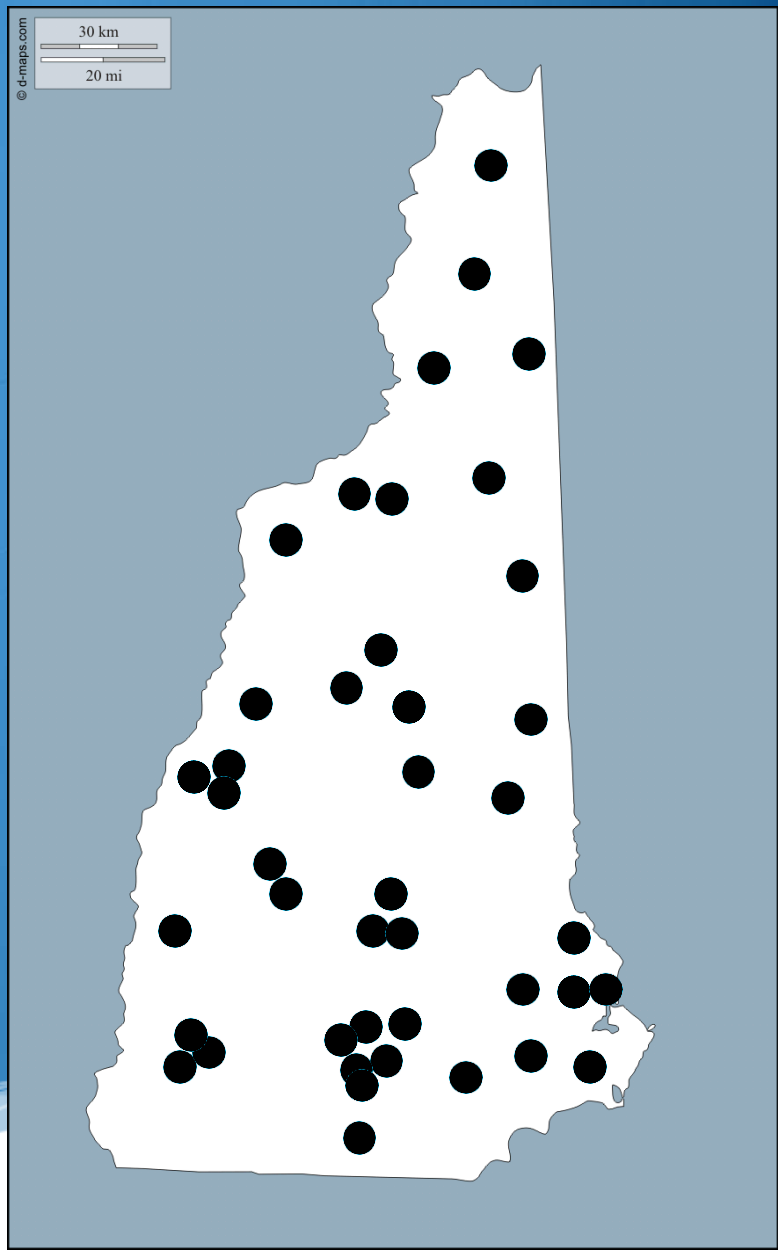
Causes of a Cancer Cluster

- Chance – random spatial clustering

Radom Spatial Clustering of Cancer

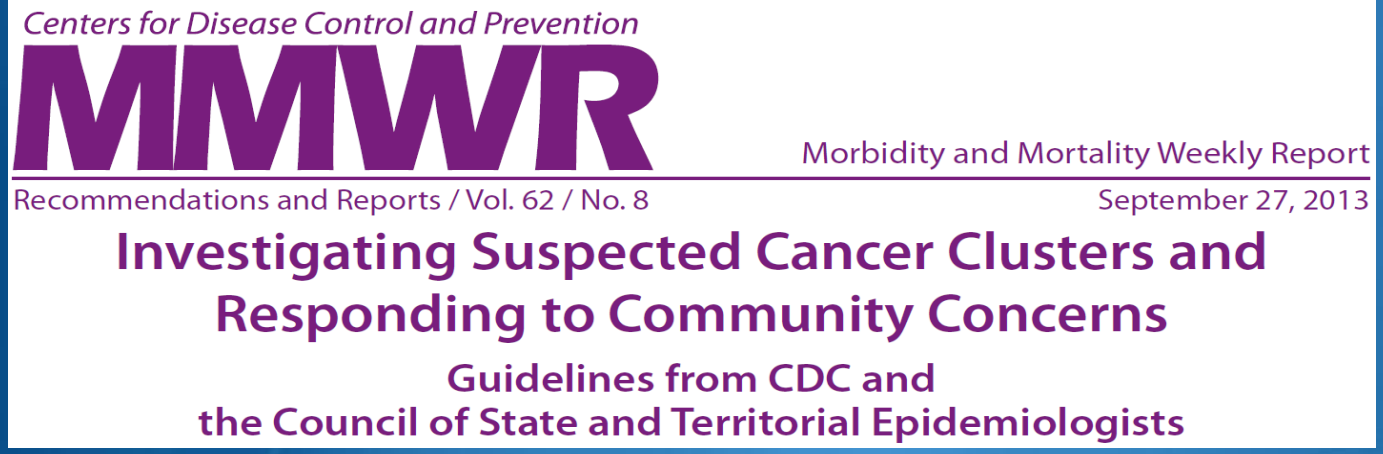


vs.



Causes of a Cancer Cluster

- Chance – random spatial clustering
- Lifestyle behaviors (e.g. smoking)
- Access to healthcare and cancer screening
- Environmental Exposures



- Guidelines on cancer cluster investigations do not recommend open-ended investigations to identify potential environmental triggers in a community in the absence of known scientific causes for a cancer because of the inability of these types of investigations to find a cause for cancer
- Never-the-less, given community concern, NH DHHS performed an assessment to see if we could identify a common exposure in the community

NH DIVISION OF Public Health Services
Improving health, preventing disease, reducing costs *for all*
New Hampshire Department of Health & Human Services

Steps in the Cancer Cluster Investigation

Step 1: Initial Response

Collect information to understand concerns & decide on follow-up.

Considerations

- Type(s) of cancer
- Frequent vs. uncommon
- Number
- Population affected
- Environmental concerns
- Scientific evidence

Step 2: Assessment

Evaluate data and perform calculations to determine if the suspected cluster is a statistically significant excess.

Considerations

- Review of literature
- Type and # of cancer
- Population
- Time period
- Geographic area
- Calculate SIR

Step 3: Feasibility

Gather information to determine if a study will identify a common cause.

Considerations

- Community input
- Case definition
- Questionnaire
- Eval possibility that cancer may be due to common exposure

Step 4: Case-Control

Case-control study to determine whether an association exists between a specific risk factor or exposure and specific cancer in question.

Questionnaire Developed Based On:

- Limited science studying causes of RMS and PPB
  - Genetic risk factors
  - Prenatal/perinatal factors (birth weight, prenatal care, pregnancy complications)
  - Parent occupation
  - Use of prescription medications
  - Behavioral exposures (tobacco and illicit drug use)
  - Medical X-ray exposure
- Known areas of environmental contamination identified by community as areas of concern within 10-town Seacoast area

Questionnaire Development & Review

- NH Dept. of Health & Human Services (DHHS)
- Cancer Registry (Dartmouth)
- Community Advisory Group (CAG) – comprised of community members, elected officials, and families affected by RMS/PPB
- Centers for Disease Control and Prevention (CDC)
- National RMS Researchers

Individuals Invited to Participate in Our Investigation:

- Confirmed RMS or PPB (Identified through State Cancer Registries)
- Diagnosed since 2001
- Age less than 20 years old (pediatric) at diagnosis
- Spent at least 28 cumulative days in the 10-Town Seacoast area* prior to diagnosis

*10-town area (“Seacoast Area”) includes: Greenland, Hampton, Hampton Falls, New Castle, Newington, North Hampton, Portsmouth, Rye, Seabrook, and Stratham.

Individuals Asked to Self-Identify as Meeting Inclusion Criteria

- 40 total individuals/families invited:
  - 26 NH residents diagnosed with RMS/PPB (entire state)
  - 14 residents in Essex County, MA and York County, ME
- Individuals identified based on confirmed diagnosis of RMS/PPB in NH/MA/ME cancer registries
- No way to confirm if most individuals ever lived or spent time in the 10-town Seacoast area

Questionnaire Response

40
Invited based on diagnosis of RMS/PPB

28
Individuals not meeting inclusion criteria because did not identify as spending time in the Seacoast area

12
Individuals known to meet inclusion criteria based on diagnosis of RMS/PPB AND who spent time/lived in Seacoast Area

7
Questionnaires Returned

Findings from Questionnaire Responses

(Summarized to protect personal information and confidentiality)

Organization of Report

- Demographics
- Geographic/environmental exposures
- Prenatal History Exposures
- Individual Medical History (“cases” = those diagnosed with RMS or PPB)
- Family Medical History
- Occupation and hobby related exposures

Demographics

- 4 females (57%), 3 males (43%)
- Average age of diagnosis: 5 years old
- All individuals were younger than 10 years old
- Diagnosed between 2005 and 2011
- 2 reported residence in the 10-town area
- 5 reported visiting the 10-town area prior to diagnosis

Geographic Exposures

- 2 reported preschool/school in Seacoast area (all different schools)
- No childcare agencies were reported
- 6 reported spending time in Portsmouth
- No other town was identified by a majority of respondents

	No. of Individuals Reporting Proximity to Site
Coakley Landfill	1
Pease Tradeport	2
Schiller Station	1
Seabrook Station	1
Portsmouth Naval Shipyard	2

Residential Water Source

- No single water system was identified by a majority of respondents

- 2 reported residential water from a public water system within the 10-town area
- 5 reported drinking water outside of the 10-town area (most public water systems)
- Total # of different public water systems: 5
- Total # of private wells: 2

Residential Air Quality

- 3 reported elevated radon gas levels in homes (all outside the 10-town area)

Prenatal History Exposures

- Average maternal age at birth: 32 years
- Average paternal age at birth: 32 years
- Average gestational age at birth: 39 weeks

Gestational Term/Birth Weight	No. of Individuals
Preterm/Low birth weight	1
Preterm/ Normal birth weight	1
Full term/ Normal birth weight	5

- No reports of tobacco or illicit drug use during pregnancy
- No reports of medical X-ray exposure during pregnancy

Medication During Pregnancy	No. of Individuals
Insulin	1
Levothyroxine	1
Vitamins (prenatal)	5

Individual Medical History

- Most individuals reported no childhood illnesses prior to diagnosis of RMS/PPB
- 3 reported common childhood ailments, including seasonal allergies, colds, asthma, etc.

Individual Medication Use	No. of Individuals
Antihistamines (oral)	2
Antipyretics/analgesics	2
Bronchodilators	2
Fluoride	1
Proton pump inhibitors	1
Steroid (inhaled or topical)	2
Vitamins	1
Other (“cold medicine”)	1

Exposure Type	No. of Individuals
Tobacco (use by case)	0
Tobacco (second-hand exposure)	1
Recreational drug use	0
X-rays (confirmed/probable exposure)	3
Other radiologic scans or nuclear studies	0
Radiation therapy	0

Family Medical History

- No family/genetic cancer syndromes reported among a majority of individuals
- No first-degree relatives with cancer
- 4 reported more distant family history of cancer

Cancer Type	No. of Individuals
Breast cancer	2
Prostate cancer	1
Melanoma	2
Thyroid cancer	1
Other tumor type	1

Occupational and Hobby Exposures

- No parental occupations were reported that suggested chemical exposure to parents
- No hobbies were reported for parents or individuals with RMS/PPB that suggested a chemical exposure

Conclusions

- No common exposures identified among individuals diagnosed with RMS/PPB to support moving to a case-control study
- The scientific literature also does not point to chemical or other environmental exposures as a cause of RMS or PPB that gives the investigation a place to focus
- No new RMS or PPB cases in the 10-town Seacoast area in children or adults over the last year

Limitations

- Our ability to find a connection to any environmental cause is limited by small numbers – both small numbers in this report, and small numbers of individuals diagnosed with RMS/PPB in the Seacoast area
- Lack of finding a common link in a small study doesn't prove there is no link, but highlights the difficulty for science to identify one

Limitations

- It is very difficult to design a questionnaire that asks about all the different types of chemicals an individual is exposed to in their everyday life
- CDC guidelines on cancer cluster investigations do not recommend open-ended investigations to identify potential environmental triggers

Next Steps

- A Legislative Commission is being formed to continue to evaluate concerns of environmental contamination and health
- We will continue to work with the Legislative Commission to address the ongoing community concerns around environmental contamination
- Provide information about cancer and help connect the community with additional resources
- We will continue to review new cases of RMS and PPB as they're reported
- Continue to investigate and address concerns as they're reported from the community

Thank You

Discussion and Questions