Rhabdomyosarcoma (RMS) and Cancer Cluster Overview

NH Dept of Health & Human Services
Governor’s Task Force Seacoast meeting
September 14, 2016
Rhabdomyosarcoma (RMS)

- Sarcomas are malignant tumors that arise from cells that often develop into connective tissue (fat, muscle, bone, cartilage)
- RMS is a type of soft tissue “sarcoma” of developing skeletal muscle
- Can arise in many locations of the body
  - Head and neck
  - Genitourinary system
  - Extremities
Represent 3-4% of all pediatric cancers
Most are sporadic without any identifiable cause
Can be associated with familial cancer syndromes (i.e. neurofibromatosis)
Individuals at risk for PPB because of underlying genetic conditions are also at increased risk for RMS
# of RMS Cases by Year in the U.S.

- Total
- Aged 0-19 Years
- Aged 20+ Years

Year:
- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013

# of Cases:
- 0
- 100
- 200
- 300
- 400
- 500
- 600
- 700
- 800
- 900

Graph showing the number of RMS cases by year in the U.S., categorized by age groups.
RMS in the U.S. from 2005-2013

- 6332 total RMS cases
  - 54% aged 0-19 years
  - 46% aged 20+ years

Rate of RMS:
- Aged 0-19 years: 0.46 cases per 100,000 persons
- Aged 20+ years: 0.14 cases per 100,000 persons
RMS in NH from 2005-2013

26 total RMS cases

- 50% aged 0-19
  - Range 0-5 cases/year
- 50% aged 20+
  - Range 0-4 cases/year

Rate of RMS per 100,000 persons:

- Aged 0-19 years: 0.46 (vs. 0.46 national rate)
- Aged 20+ years: 0.15 (vs. 0.14 national rate)
Update on the Seacoast Cancer Cluster Investigation
Objectives

- Review cancer cluster criteria
- Review the DHHS protocol for responding to expressed concerns regarding potential cancer clusters
- Update on DHHS progress on RMS/PPB Cluster Investigation
What is a cancer cluster?

- **Greater than expected number** of observed cases than would typically be observed in a similar setting
- **Of cancer cases** that involve the same type of cancer or different types that science has proven have the same cause
- That occurs within a **carefully defined group of people**
- In a defined **geographic area**
- Over a **period of time**
What causes cancer clusters?

- Coincidental spatial clustering
- Better access to health care
- Lifestyle behaviors
- Environmental exposures
What role do chemicals play in causing cancer?

- Many people believe chemicals cause most cancers
- Research shows the role they play is small and unclear
- Some common chemicals with known links include (arsenic, asbestos, benzene, DDT, formaldehyde)
What role do environmental exposures play in causing cancer?

Getting cancer from environmental exposures depends on:

- The kind of exposure you come in contact with
- How much (dose)
- How long contact lasted (exposure)
- How often you were exposed
- How it entered your body (eating, drinking, breathing, touching)
- Your health at the time of contact

Proximity to environmental contaminants does not mean it has entered your body or will cause cancer.
The protocol was developed...
Based on:

- Knowledge & Understanding
- Past Experience
- CDC Guidelines
- Review of Other Protocols

With input from:

- Division of Public Health Services staff across levels
- Department of Environmental Services staff
Why have a protocol?

- To protect privacy
- To set expectations about feasibility
- To mitigate fear
- To prevent emotional distress of individuals
- To prevent action to address a perceived health risk prior to taking responsible steps to assess a perceived health outcome
- To assure that concerns are responded to according to best practice
What is the Department’s Cancer Cluster Investigation Process?

**Step I: Initial Contact & Response**
DPHS collects information to determine whether concerns warrant follow-up

**Step II: Assessment**
DPHS completes calculations to determine if the suspected cluster is a statistically significant excess

**Step III: Feasibility**
DPHS gathers information from cases to determine if it is likely that a study will show that cases relate to a common cause

**Step IV: Case-Control**
Case-control study conducted to determine whether an association exists between a specific risk factor or chemical

**Considerations**
- Multiple types
- Common vs. rare
- Large number
- Unusual sex or age
- Environmental concerns
- Exposure experienced by individual
- Biological plausibility

**Research & Calculations**
- Case definition
- Review of literature
- Basic cancer analyses
- Age of dx trends
- Calculate expected #
- Observed/Expected

**Considerations**
- Case definition
- Questionnaire
- Study protocol
- Determine plausibility that cases and contaminants are associated
- Convene community for input
What is a cancer cluster?

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Of cancer cases that involve the same type of cancer or different types that science has proven have the same cause

That occurs within a carefully defined group of people

In a defined geographic area

Over a period of time
**RMS Investigation**

**Step I: Initial Response (3/14-2/15)**
- Contacted by Rye residents
- Concerns about RMS cases
- Concerns about environmental exposures

**Step II: Assessment (3/15-2/16)**
- 5-town area (Ryes, New Castle, Portsmouth, Greenland, North Hampton)
- RMS SIR 6.0 (95% CI 1.9-18.5)
- PPB SIR 20.3 (95% CI 5.1-81)

**Step III: Feasibility (2/16-present)**
- Finalizing case definition
- Established Community Advisory Group (CAG)
- Developing case questionnaire
  - Review of literature on RMS and PBB
  - Review of animal studies
  - Review of known contaminants in the area
- Developing protocol for case series
Step III: Feasibility (2/16-present)

- Finalized case definition
- Established Community Advisory Group (CAG)
- Developed case questionnaire with input from national experts and the CAG
- Developed investigation protocol and reviewed with DHHS legal and reviewing with the CAG
- Requesting exemption from IRB
- Piloting case questionnaire
- Contact families who have contacted us
- Begin provider-based outreach
For More Information

Whitney Hammond
Director, Chronic Disease Section
603-271-4959
whitney.hammond@dhhs.nh.gov
http://www.dhhs.nh.gov