

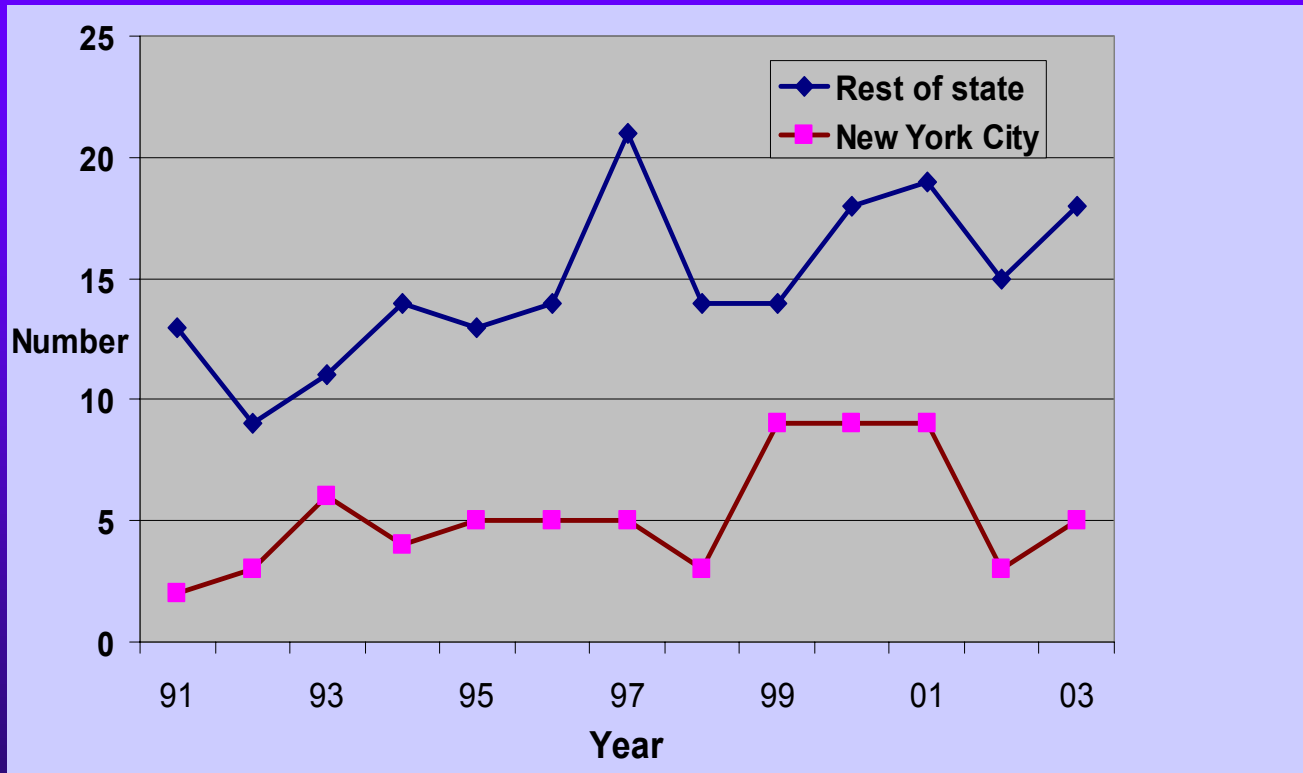


# Surveillance of CJD in New York State: A Team Approach

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# Number of Deaths by Year





# CJD Reporting

## Legal mandate to report:

- Reportable since 1986 in New York State under Public Health Law which mandates reporting of dementias to the Alzheimer's Disease and Other Dementias Registry  
(New York State Public Health Law, Article 20)
- Transmissible Spongiform Encephalopathies reportable to NYCDOH since July 28, 2001  
(New York City Health Code section 11.03)



# Role of Departments of Health

## **Enhance surveillance of CJD and vCJD:**

Improve diagnosis (through increased use of specialized diagnostic testing and use of of biopsy and/or autopsy)

Earlier reporting through increased collaboration between partners, physicians and health care facilities

Ensure adherence to established infection control procedures

Advance knowledge of CJD among people interacting with patients and families



# Sources of Data

- Direct reporting by physicians, institutions and labs
- Reports from the National Prion Disease Pathology Surveillance Center
- Coordination of reporting with New York City Department of Health and Mental Hygiene
- Review of death certificate files (all listed causes)
- Review of hospital discharge database
- Review of nursing home assessment database



# Current Partners

Centers for Disease Control and Prevention

New York State DOH

National Prion Disease Pathology  
Surveillance Center, Division of  
Neuropathology

New York City DOH

CJD Foundation

# CJD Workgroup—Exploring the Issues Together

- Improve diagnosis
- Enhance early reporting
- Improve awareness of CJD infection control procedures
- Educate individuals who interact with CJD patients







# Importance of Accurate Diagnosis

## To patient and family:

- Ensures a treatable disease is not missed
- Aids in future decisionmaking on behalf of the patient
- May present opportunity for genetic testing in family members
- May present opportunity for participation in clinical trials of preventive agents





# Importance of Accurate Diagnosis

## To public health:

- Ensures vCJD is identified
- Monitors trends in CJD
- Identifies potential for iatrogenic spread of disease
- Permits research on prion disease that may be applicable to other neurological diseases



# Testing for CJD

## Definitive tests:

- immunohistochemical exam of fixed brain tissue

- Identification of protease-resistant protein in unfixed brain tissue

## Clinically useful but not definitive:

- 14-3-3 protein in cerebrospinal fluid

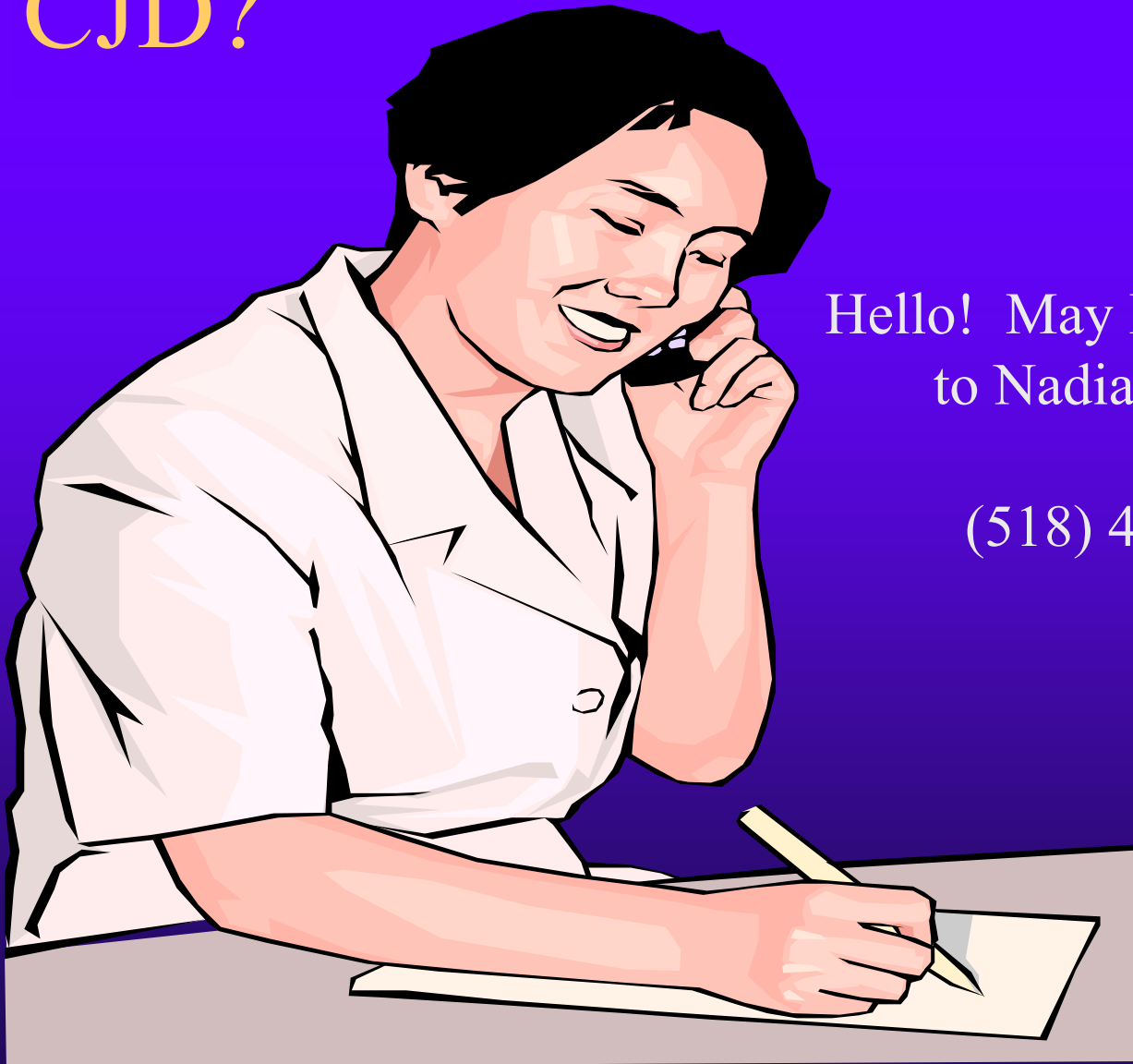
- DNA studies of blood, brain or other tissues



# Reducing Barriers to Autopsy

- Involvement of support organizations could help reduce lack of acceptance
- Development of non-invasive tests could reduce concern for contamination and family acceptance as barriers
- In the meantime, we are collaborating with the National Prion Disease Pathology Surveillance Center to establish a network of qualified pathologists to conduct autopsies

# Have a possible patient with CJD?

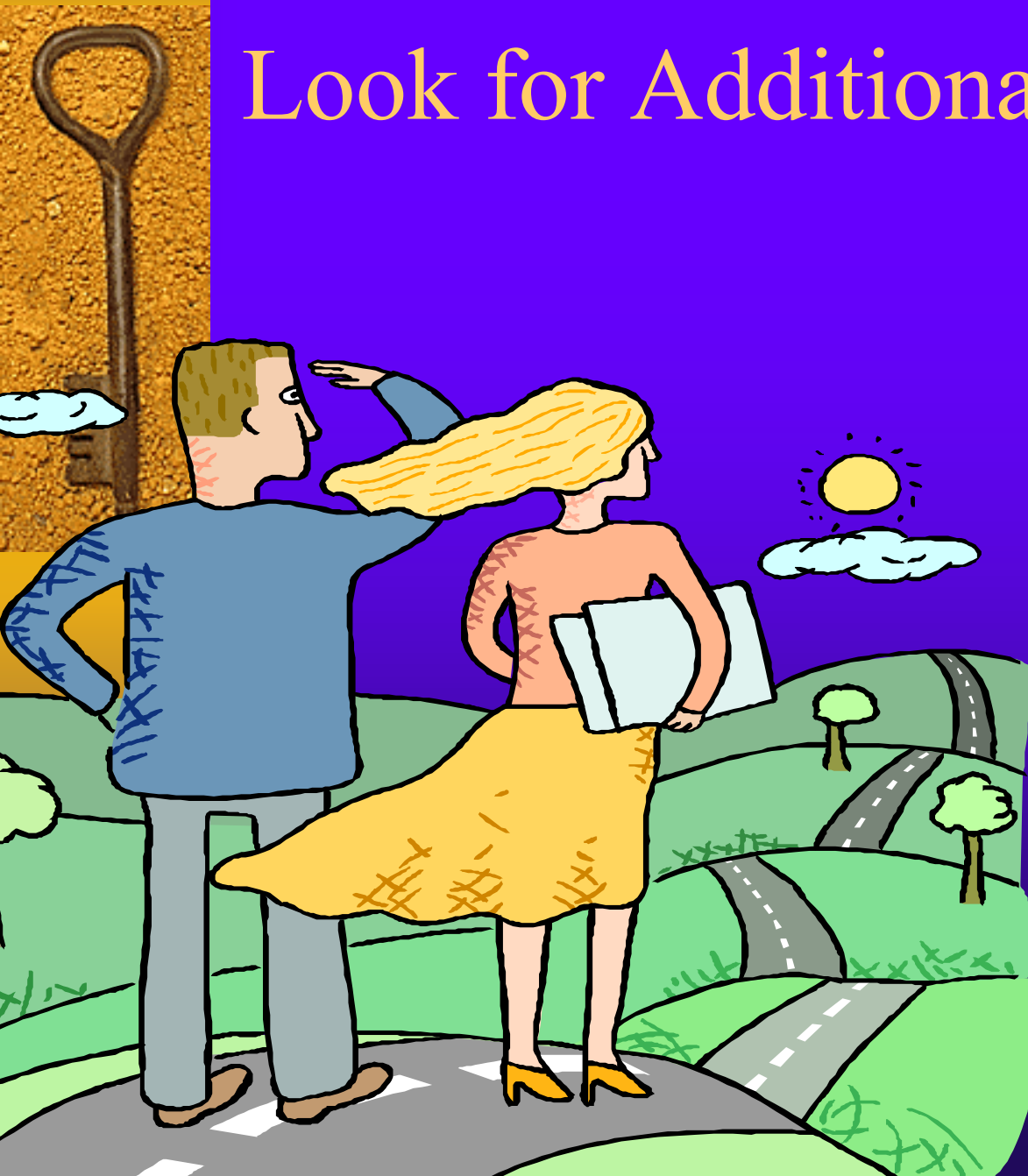


Hello! May I please speak  
to Nadia Thomas?

(518) 473-7817



# Look for Additional Resources



Additions to the Health Information Network and NYSDOH public web site

Guidelines and sample protocols, especially for infection control practitioners

List of slide sets available for hospital grand rounds

Infection control protocols in DVD format for others with CJD concerns

Questions?

