

# Educational Outreach to Individuals at Risk for Hereditary Colon Cancer

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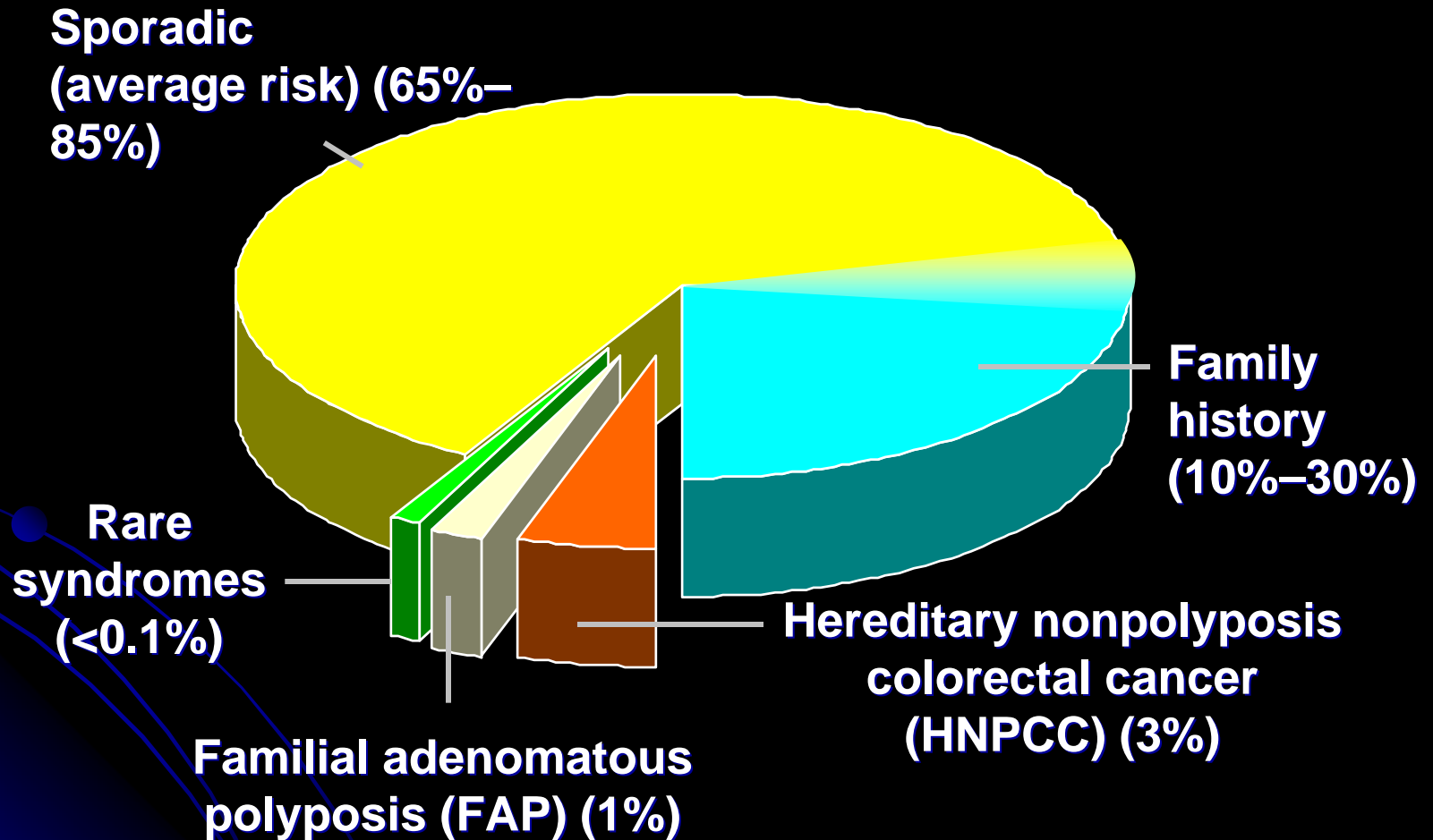
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# Colorectal Cancer

- 145,00 cases each year
- 56,000 deaths



# HNPCC

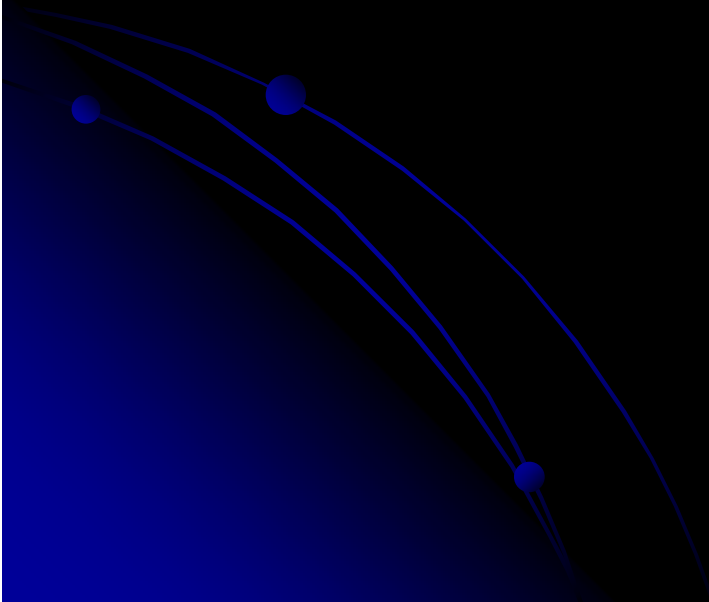
- Also called Lynch Syndrome – 3% of colon cancer
- Due to mutations in mismatch repair genes
- 80% lifetime risk of colon cancer
- Increased risk for other cancers
  - 60% risk for endometrial cancer
  - Other cancers: ovary, stomach, urinary tract, small intestine, brain and biliary tract
- Different medical management recommendations
  - Frequent, earlier colonoscopies
  - Prophylactic surgical options

# Genetic Testing

- Most referrals are for breast cancer
  - Only 10% of referrals are for colon cancer
- Most informative to test affected first
- Physicians often do not discuss genetic testing options with patients
  - Testing process can be confusing
  - Limited time with patient
  - Timing is not right
  - Lack specific knowledge in hereditary cancer

# Project Purpose


- To increase awareness about hereditary colon cancer among high-risk cases identified through the Colorado Central Cancer Registry



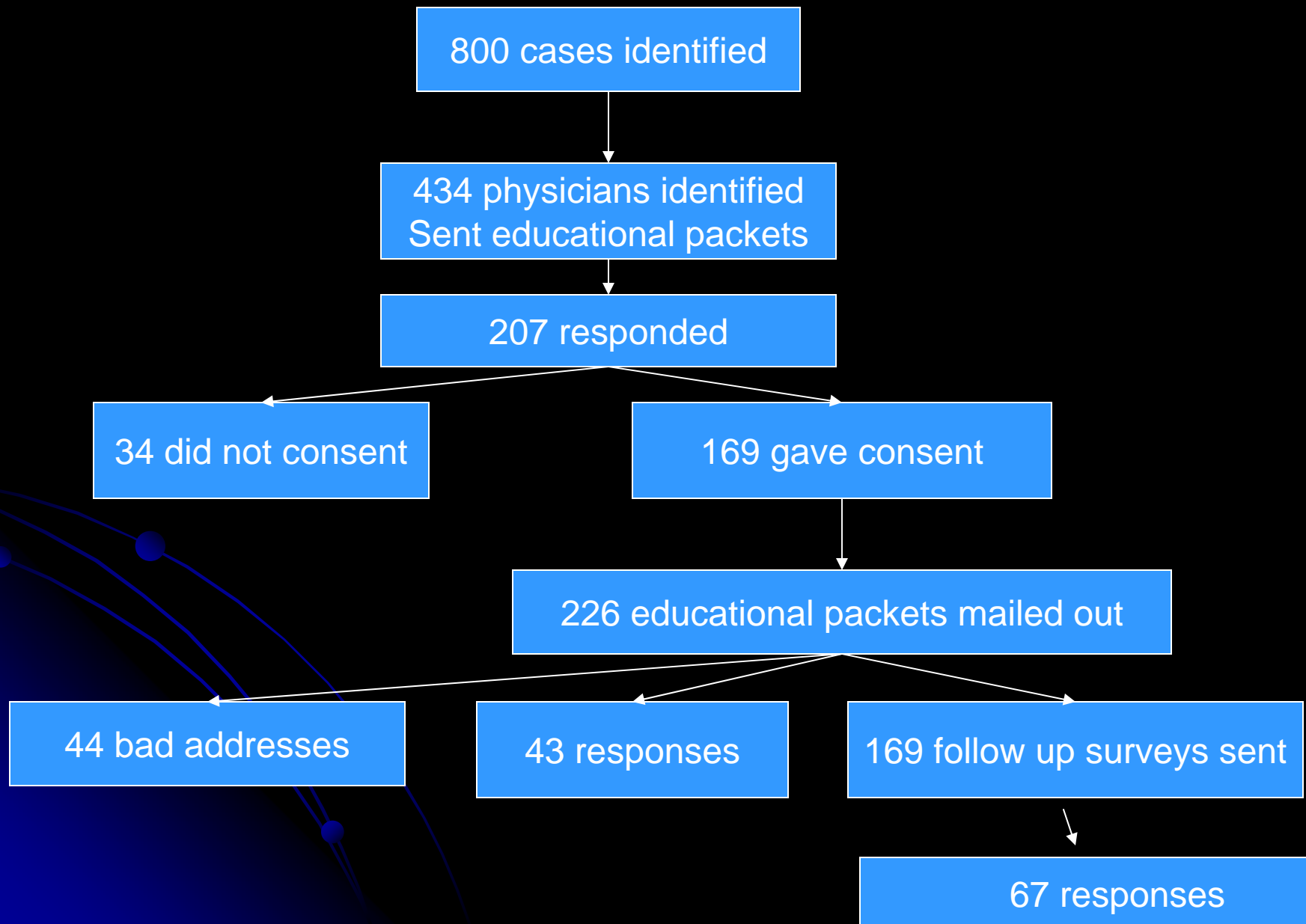
# Project Aims

1. Utilize state cancer registry to identify at-risk individuals
2. Conduct mail-based educational outreach about hereditary colon cancer to
  - physicians
  - their patients with colorectal cancer
3. Implement a toll-free information line
  - answer general questions, provide referrals, or provide telephone cancer risk assessments
4. Evaluate feasibility and effectiveness of using state cancer registry for identifying at-risk individuals for hereditary cancer

# Target Population

- Individuals diagnosed with:
    - CRC under age 50
    - Metachronous or synchronous CRC or other Lynch syndrome related cancers
    - CRC under age 60 that exhibits certain histologies consistent with hereditary cancer
  - Cases diagnosed within past 5 years
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# Outreach Workflow



# Physician Survey Response

	Yes	No	Not Sure
Was the information easy to understand?	159/ 95%	8/ 5%	
Will the information be useful to your patients?	143/ 85%	4/ 2%	22/13%
Do you provide information about cancer and genetics to your patients?	130/ 77%	34/21%	4/ 2%
The registry should send information to cases at risk, no physician consent needed	99/ 60%		
The registry should send information, consent is needed	51/ 30%		
The registry should not send information		5/ 3%	
Not sure if registry should send information			12/ 7%

# Physician non-consent

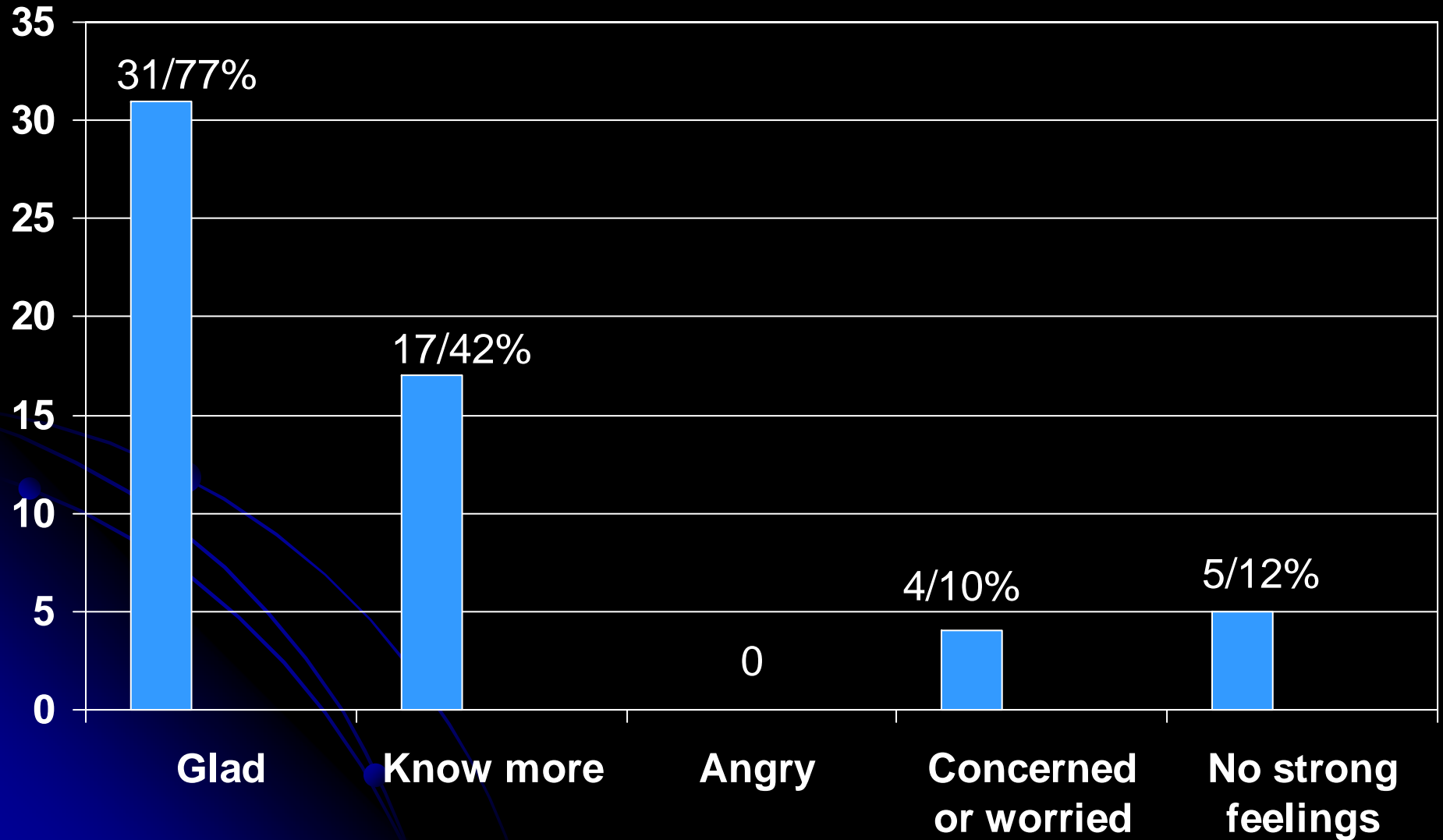
- 34 did not give consent to have information sent to their patients
  - 4 – patient expired
  - 10 – no longer following the patient
  - 2 – patient had already been tested
  - 5 – not their patient
  - 3 – no reason given
  - 1 – thought it violated HIPPA
  - 3 – already do testing and didn't want to refer out
  - 2 – Age of patient, terminal status

# Educational Outreach

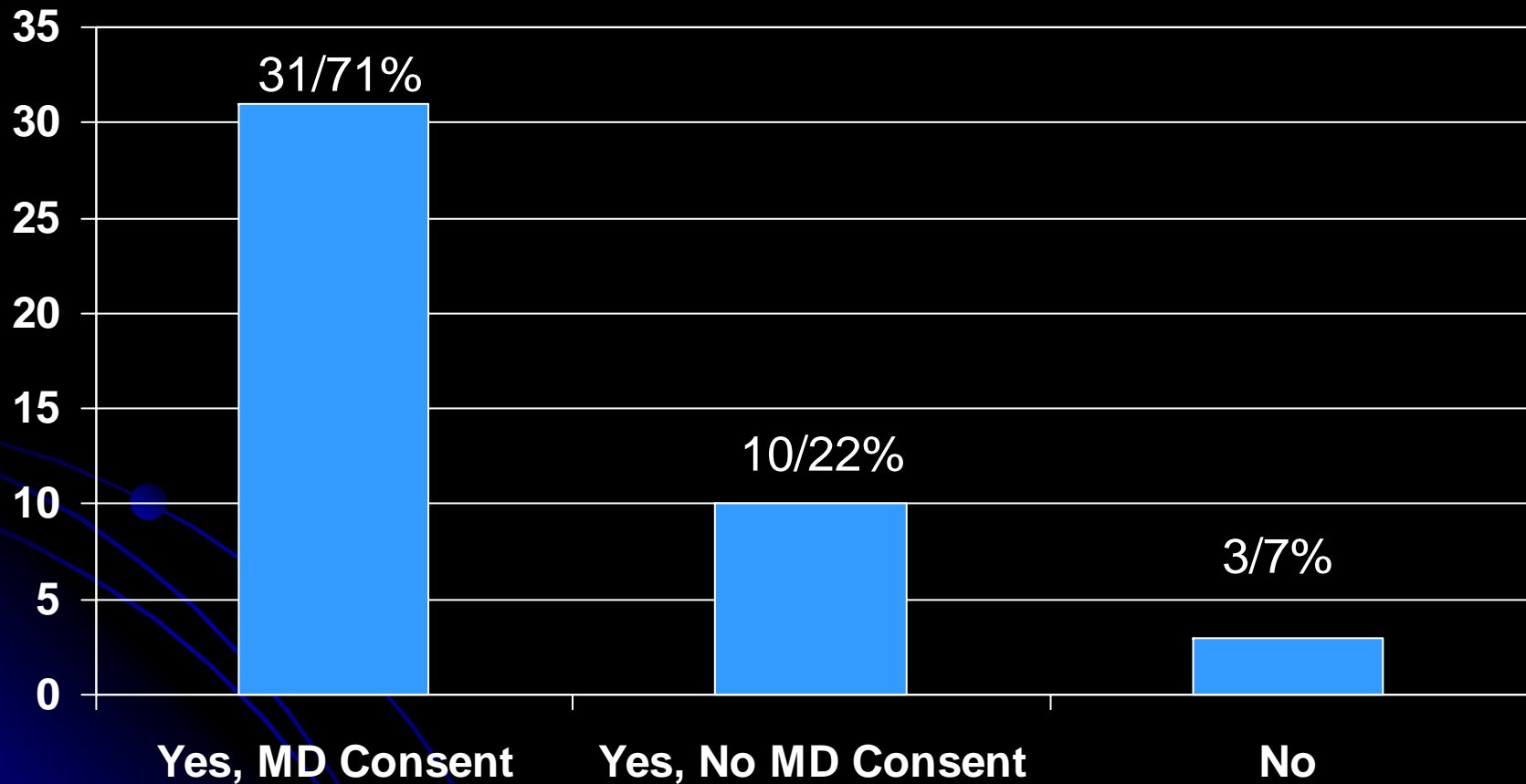
- Response rate: 24% (N=43/191 mailed)
  - 20 females, 23 males
  - Age range 33-91

	Yes	No	Not sure
Was the information clear?	42 97%	1 3%	
Will the information be useful to you?	30 71%	3 7%	9 21%

# How Did You Feel About Getting The Information?



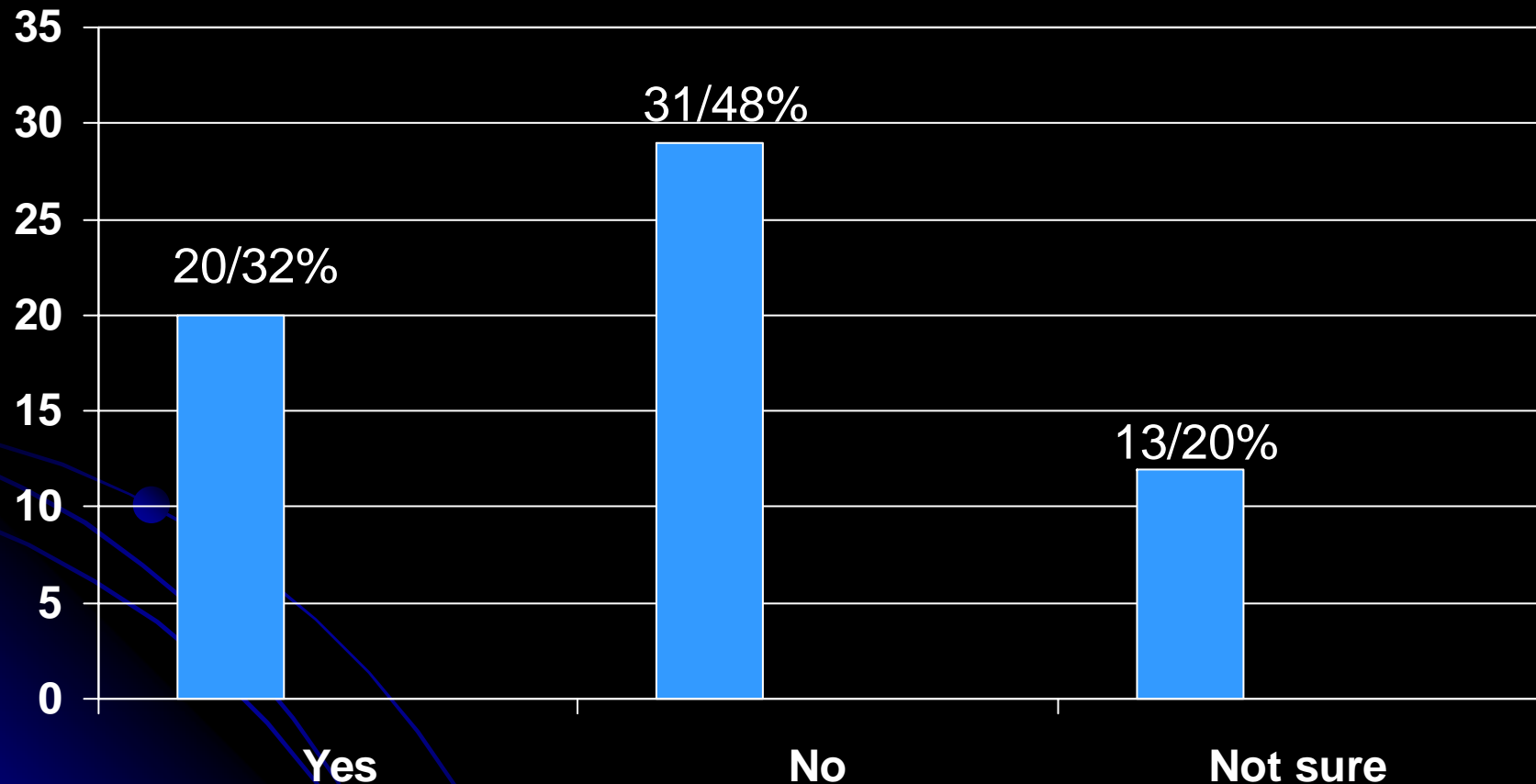
# Should the Registry Send Out Information to Individuals At Risk?



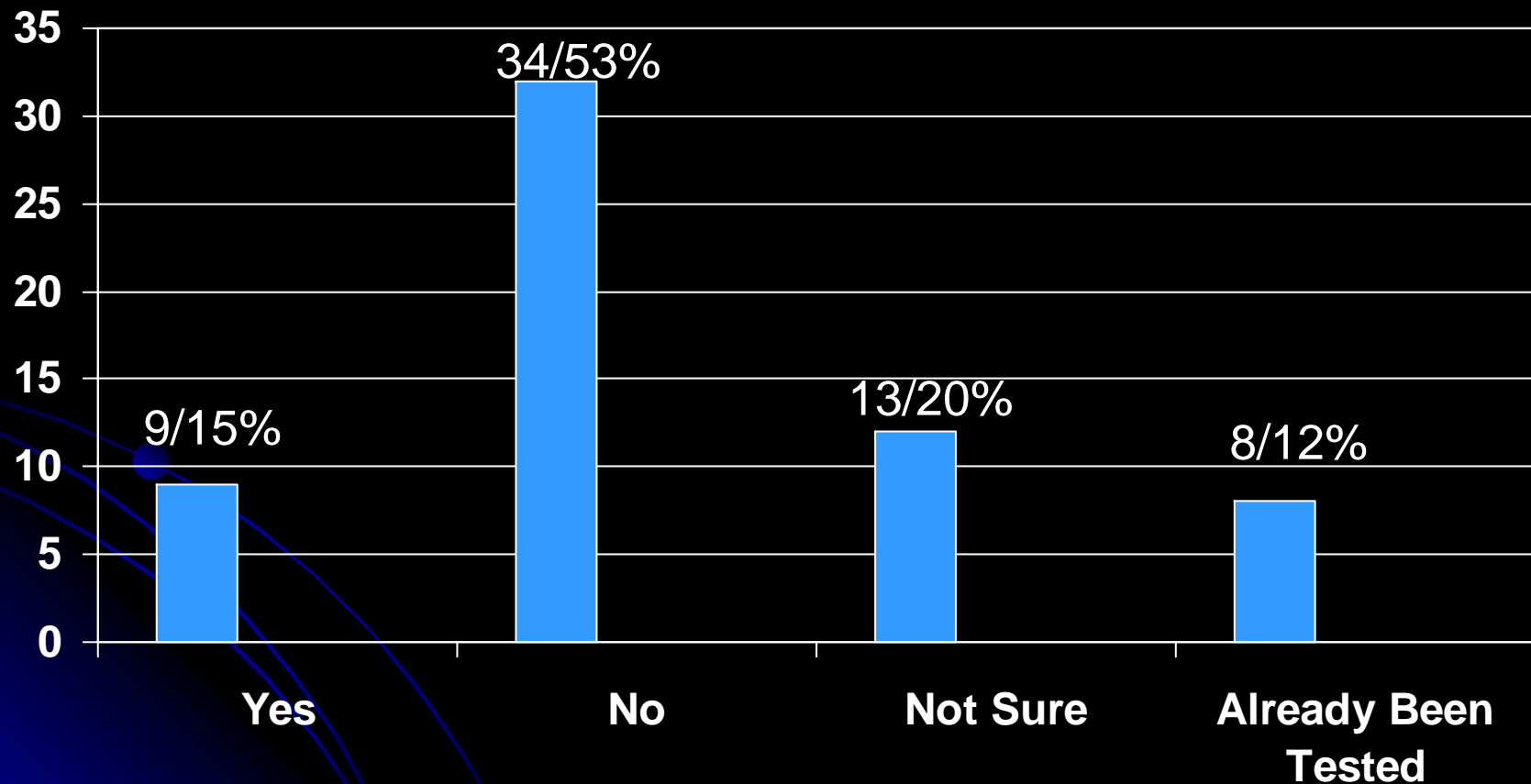
# Follow Up Survey

- 166 surveys sent 4 months later
- 67 returned the survey
  - Response rate 40%
  - 1 patient expired
- 31 males, 36 females
- 74% remembered getting the brochure
- 63% read the brochure

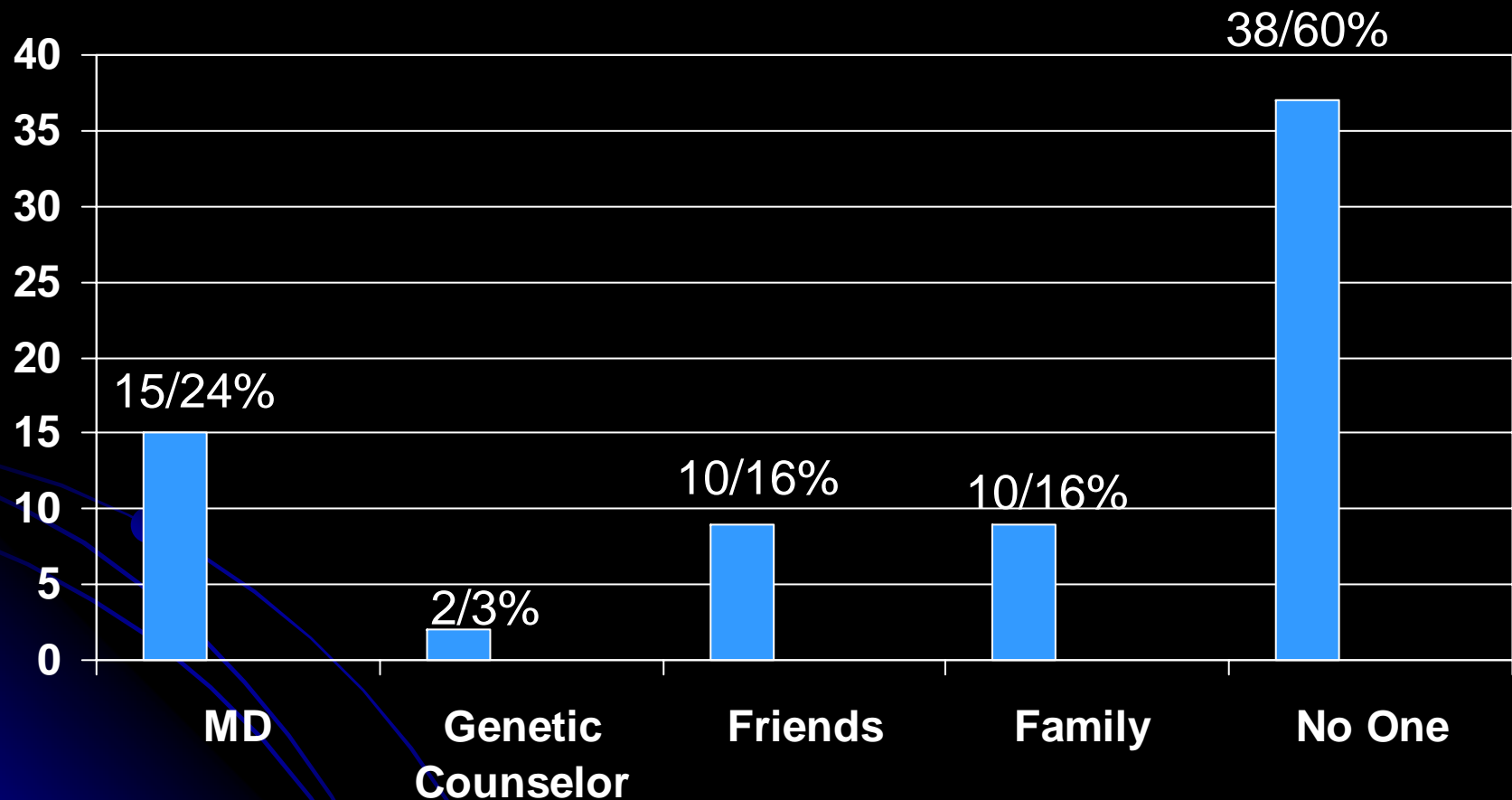
# In the Past 4 Months, Did You Have a Cancer Risk Assessment or Intend to in the Near Future?



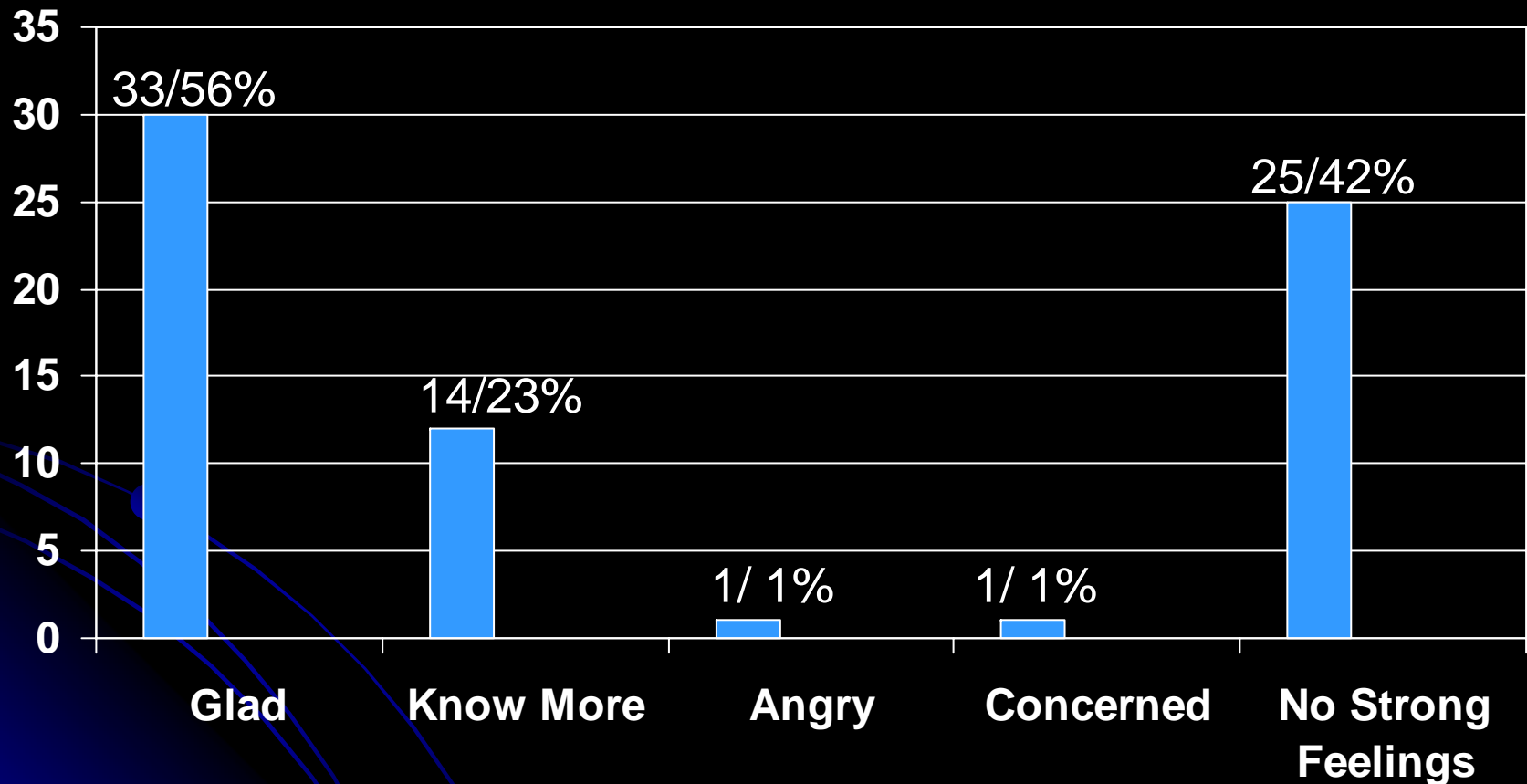
# In the Past 4 Months, Did You Have Genetic Testing or Intend to in the Near Future?



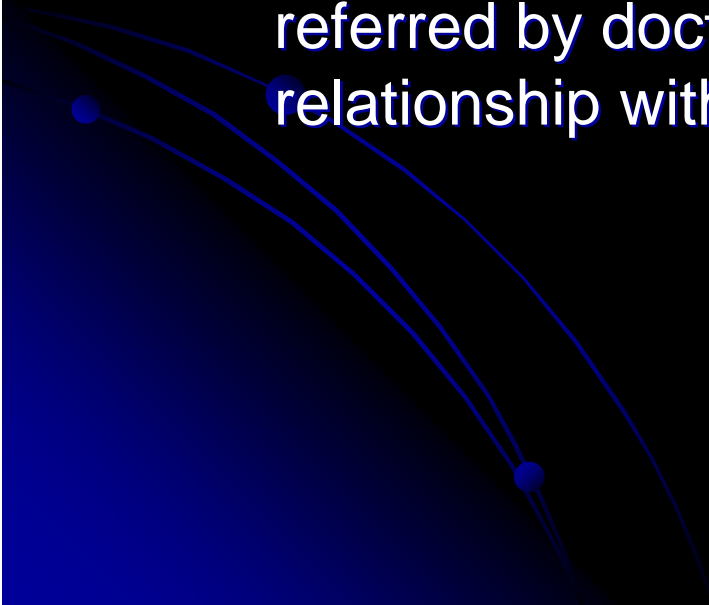
# Have You Discussed Cancer Risk Assessments With Anyone?



# How Do You Feel About Getting This Information?



# Providing Telephone Genetic Counseling

- No calls to toll free line
    - No referrals/counseling provided
  - Why?
    - May prefer talking with doctor directly
    - May be more effective if telephone counseling referred by doctor or after establishing clinical relationship with counselor
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# Is using registry a viable approach?

- Overall, physicians and individuals were supportive
- Cases preferred physician be involved, but physicians did not feel it was necessary
- Very few negative responses
- Registry may consider doing outreach prospectively
- May require physician/patient education at time of enrollment into registry