

# INCTR Retinoblastoma Strategy Group Report

Understanding Problems Faced by  
Parents of Children with  
Retinoblastoma Prior to Treatment  
March 3, 2007

# Strategy Group History

- Initial Meeting, November, 1999
  - Purpose: Common Problems Encountered
  - Consensus: Late presentation of patients, lack of professional awareness, need to develop treatment strategies for advanced retinoblastoma

# Development of the Questionnaire

## ■ January, 2001

- Group of interested investigators met to design a questionnaire for parents of children with retinoblastoma in order to:
  - Document late presentation
  - Document the reasons for late presentation
    - Due to parents
    - Due to health care professionals

## ■ August, 2001

- Protocol approved by INCTR Ethical Review Committee
- Participant enrollment began

# Participating Institutions

- Originally, 10 institutions representing 8 countries agreed to participate
- Study expanded to include more centers within certain countries or other world regions
- Data submissions have varied over time
  - Investigator departures
  - Workload often prohibits participation
  - Changing or fluctuating patterns of referrals

# Participating Institutions

## ■ Institutions

- Mexico - Instituto Nacional de Pediatría
- Guatemala – University Francisco Marroquin
- Bolivia – El Instituto Oncológico del Oriente Boliviano
- Brazil – Albert Einstein Hospital
- Nigeria – OAUTHC Obafemi Awolowo University
- Tanzania – Ocean Road Cancer Institute
- Zimbabwe – University of Zimbabwe
- Turkey - Ankara University and Dokuz Eylül University
- India - All India Institute of Medical Sciences, Tata Memorial Hospital, Cancer Institute Chennai
- Pakistan - Shaukhat Khanum Memorial Hospital

# Number of Questionnaires by Region

Region	No of Participants %
India	158 (41%)
Latin America	103 (27%)
Turkey	64 (16%)
Pakistan	36 (9%)
Africa	27 (7%)
Total	388

# Total Surveys Analyzed

	No	(%)
Mothers	179	46.1
Fathers	176	45.4
Guardians	32	8.2
Patient	1	0.3
Total	388	

# Age of Participants

	<i>Mean Age</i>	<i>Range</i>
Fathers	33	21 - 60
Mothers	29	17 - 47

# Age of Parents

- Regardless of who gave the interview
  - mother, father or guardian:
    - Fathers were on average 4.7 years older than mothers ( $p < 0.00001$ )
    - 73.5% of fathers were 1-9 years older than mothers
    - 14% of fathers were 10-40 years older than mothers

# Characteristics of the Children

## Sex

*Males* 220 (57%)

*Females* 168 (43%)

## Age

*Range* 1 month– 15 years

*Median* 29 months

African and Indian children  
tended to be older

# Education Level of Parents

<i>Level</i>	<i>Fathers</i>	<i>Mothers</i>
Illiterate	11%	22%
Primary	37%	34%
Secondary	32%	32%
University	17%	11%
Other	1%	1%
Unknown	2%	1%

# Urban Versus Rural

Region	Urban %	Rural %
India	37	63
Latin America	56	44
Turkey	63	38
Pakistan	61	39
Africa	26	74

*More African & Indian families  
were from rural areas  
( $p=0.0001$ ).*

# Socioeconomic Status

Region	Low	Moderate	High
India	60.5%	29.9%	9.6%
Latin America	79.4%	20.6%	0
Turkey	71.9%	26.6%	1.5%
Pakistan	72.2%	27.8%	0
Africa	63%	37%	0

# Family History of Retinoblastoma

Total Number of Families 27  
(7.1%)

*There was no significant difference in this percentage between regions or institutions.*

# First Person to Notice a Problem

<i>Relationship to Child</i>	Total No (%)
Mothers	245 (63.6)
Other Relatives	63 (16.4)
Fathers	53 (13.8)
Health Care Providers	7 (1.8)
Others	17 (4.4)

Note: Missing Data, 3

# First Sign Noticed

Leukocoria	254 (65.5%)
Strabismus	69 (17.8%)
Red eye	17 (4.4%)
Protruding eye	11 (2.8%)
Loss of vision	10 (2.6%)
Change in vision	9 (2.3%)
Others	18 (4.6%)

*The first sign noticed was sometimes not the same sign that made the parent seek advice*

# Action Taken by Parents After First Sign

Action Taken by Parent	Total (%)
Sought advice or help	229 (59.2)
Continued to Observe Child	153 (39.5)
Treated by parent	5 (1.3)

*There was only a slight tendency for better educated parents to seek advice, but this was not statistically significant.*

# Who Parents Sought Advice From

Advice	Total (%)
Traditional healers	7 (1.8)
Family doctors	48 (12.5)
Pediatricians	53 (13.8)
Ophthalmologists	236 (61.3)
Others	41 (10.6)

# Actions Taken After Initial Advice

Action Taken	Total (%)
Continued to observe	34 (8.8)
Followed advice given	139 (36.1)
Sought a second opinion	103 (26.7)
Saw a specialist as advised	109 (28.3)

# Extent of Disease

Unilateral Involvement	235	(61%)
Bilateral Involvement	147	(38%)

# St Jude Stage

Stage I	45	12%
Stage II	201	52%
Stage III	80	21%
Stage IV	29	7%
Not done or UNK	33	9%

# St Jude Stage by Region

Region	I	II	III	IV
India	8%	64%	23%	5%
Latin America	9%	61%	26%	5%
Turkey	35%	53%	5%	6%
Pakistan	8%	42%	39%	11%
Africa	0	20%	30%	50%

# St Jude Stage

- Turkey had mostly Stage I and II patients
- Latin America, India and Pakistan had mostly Stage II and III patients
- Africa had mostly stage III and IV patients
- These differences were significant ( $p < 0.00001$ )

# Association with Stage

- Children from rural areas had higher stages of disease ( $p < 0.0001$ )
- Older age of child at diagnosis was associated with higher stage of disease ( $p < 0.00001$ )
- Lower socioeconomic status was associated with higher stage of disease ( $p = 0.0001$ )
- Father's Education Level was associated with St Jude Stage
  - Lower education level was associated with higher stages of disease ( $p < 0.00001$ )

# Stage and Time Interval (First Symptom to Diagnosis)

- Longer time intervals between first sign/symptom to diagnosis associated with higher stages of disease  
( $p < 0.0001$ )

# Father's Education Level and Time Interval (First Symptom to Diagnosis)

Time intervals associated with father's education level ( $p < 0.00001$ )

Lower education levels associated with longer time intervals between first sign/symptom to diagnosis

# Public Awareness – Access to Radio

<i>Region</i>	<i>Have a Radio</i>	<i>Listen to Radio</i>
India	51.9%	51.9%
Latin America	83.5%	67.9%
Turkey	79.7%	45.3%
Pakistan	36.1%	16.7%
Africa	88.9%	88.9%

# Public Awareness – Access to Television

<i>Region</i>	<i>Have a TV</i>	<i>Watch TV</i>
India	50.6%	53.2%
Latin America	82.5%	75.7%
Turkey	98.4%	84.4%
Pakistan	63.9%	66.7%
Africa	25.9%	25.9%

# Public Access to Media

- Public awareness campaigns might be better directed to “media” that is accessible to those affected
  - Radio for African countries
  - Radio and TV for India
  - TV for Latin America, Turkey and Pakistan

# Future Plans for Questionnaire Study

- Data “cleaning” and follow up with investigators to complete missing data is in progress
- Data will undergo final statistical analysis in 2007
- Study writing committee to be established in Sao Paulo
- Group publication is planned for 2007

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(translation of forms into Spanish and  
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# Retinoblastoma Strategy Group

